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ABSTRACT

This national symposium was held to identify critical issues and "best practices" in providing services for individuals with deaf-blindness and to develop strategies for future actions. The symposium focused on several specific topical areas in an effort to find ways in which resources might be marshalled at the federal, state, local, family, and personal levels to address the issues collectively. The topical areas discussed included: early intervention, population/demographics, family services, psychosocial services, communication, personnel preparation, educational services, independent living, adult services, self-determination, and technology. Presentations and reactions are provided for each topical area. Recommendations of focus groups are also presented, in the areas of education, personnel preparation, families, adult services, funding, and research and development. The text of the keynote presentation by Joyce Ford, titled "Beyond Typical Thinking, Beyond Today," is also included. References accompany most of the presentations. (JDD)

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ED 363 046

Proceedings of the National Symposium on Children and Youth Who Are Deaf-Blind

John W. Reiman
Pattie A. Johnson

Editors

1992

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EC 302502

The National Symposium on Children and Youth Who Are Deaf-Blind was held December 5-7, 1992, in McLean, Virginia.

The symposium and the preparation of the proceedings were supported through Grant No. H025Q10001. The symposium was the result of a cooperative agreement between Teaching Research Division, Western Oregon State College in Monmouth, Oregon and the Office of Special Education Programs (OSEP) of the United States Department of Education. The opinions expressed herein do not necessarily reflect the position or policy of the U.S. Department of Education, and no official endorsement is inferred.

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August, 1993

Opening Remarks (excerpt)

This symposium, supported by the U.S. Department of Education, was conceived as a transdisciplinary endeavor. Expert presenters and reactors from 10 disciplines or content areas will offer snapshots of current practice and their visions for the future. Were we to stop there, we would have a ***multi****disciplinary or* ***inter****disciplinary format. But we're taking it one giant step further. Focus groups, after each pair of presentations, will allow* ***all*** *of us (parents, professionals, and consumers) to direct our collective* ***trans****disciplinary attention toward a* ***single goal****—a brighter future for children and youth who are deaf-blind.*

Everything *we do in the next two and a half days addresses this future. In the end, to have been effective, this symposium will not have deliberated about* ***who is*** *right, but about* ***what will be right*** *for children who are deaf-blind and the people who love and serve them. Competition must yield to community and a new sense of* ***transdisciplinary partnership*** *forged. Disparate interests must be transcended and the greater whole embraced. With great excitement and anticipation, we welcome you and invite your fullest participation.*

John W. Reiman

December 6, 1992

Acknowledgements

Organization and implementation of this symposium presented a complex task. My thanks to Pattie Johnson and Clover Stein, whose tireless efforts paid off in the production of a symposium that was, by all accounts, an efficiently and smoothly run endeavor. Pattie Johnson additionally did an extraordinary job of readying these Proceedings for publication. Pattie's persistence and tenacity in attending to the myriad of details associated with an effort of this magnitude were invaluable assets. Richelle Hammett's excellent planning and coordination (assisted by Rhonda Jacobs), for accommodations, accessibility, and interpreter services facilitated fluid communication between all symposium participants—at least 15 of whom were deaf, blind, or deaf-blind. More than 30 professional sign language interpreters were contracted for the symposium and delivered a high quality service that was noted favorably by all participants. Volunteers from Bloomsburg State University enthusiastically helped in many areas. Steve Johnson's initial conceptualization of the successful focus group process was very much appreciated. Finally, my thanks to Charles Freeman, USDOE/OSEP Project Officer whose support, gentle guidance, and thoughtful suggestions made a significant contribution. -JR

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BACKGROUND

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HISTORICAL NOTE

Charles Freeman, USDOE Project Officer

The following describes the general sequence of actions that led to the National Symposium on Children and Youth Who Are Deaf-Blind.

Since the establishment of the Services for Children with Deaf-Blindness Program in the 1960s, the federal government has sponsored a number of national meetings to promote better services for children and youth who are deaf-blind. The Office of Special Education Programs (OSEP), supported by recommendations from individuals and organizations, desired to convene a conference to explore a number of critical issues, many of which have arisen due to changes in the nature and needs of this population in the past few years.

To sponsor such a meeting, the Severe Disabilities Branch of the Office of Special Education Programs started work drafting a program priority in early 1990. On July 31, 1990, the Secretary published in the Federal Register a notice of Proposed Funding Priorities for fiscal year 1991 and invited public comment. As no public comment was received specific to the symposium, OSEP published Final Funding Priorities for fiscal year 1991 in the Federal Register on January 22, 1991 inviting applications for an 18-month project to conduct a two and half-day symposium related to children and youth who are deaf-blind. As a result of the limited funds available, this priority specified that the symposium involve approximately 60 selected participants who represented a cross-section of disciplines and services to children who are deaf-blind. The symposium's commission was to identify critical issues and "best practices" and develop strategies for future actions. *The symposium was not intended to develop a long list of actions for which the federal government was exclusively responsible, but rather, through the process of focusing on 10 topical areas, to find ways in which resources might be marshalled at the federal, state, local, family, and personal levels to address these issues collectively.*

In response to the invitation, two applications were submitted to the CFDA 84.025Q grant competition. On May 15, 1991, a panel of three peer reviewers met to evaluate the two applications and make funding recommendations to the Severe Disabilities Branch. Upon completing the grant award process, Teaching Research, Monmouth, Oregon was awarded a cooperative agreement on September 24, 1991, to conduct the project.

In keeping with the priority, the grantee accepted the challenge of completing all of the tasks necessary to conduct the project in accordance with the structure described in the priority. The National Symposium on Children and Youth Who Are Deaf-Blind was held December 5-7 1992.

♦ ♦ ♦

PLANNING THE SYMPOSIUM

John W. Reiman

Preparation for the symposium began in earnest during October of 1991 when the transdisciplinary planning committee (as proposed in the initial grant application) convened. Committee members are listed here:

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At this meeting the committee identified the symposium's 10 key topical areas, generated lists of possible subtopics in each area, and began the process of identifying possible presenters, reactors, focus group leaders, and at-large participants. A correspondence- and phone-based feedback loop was created to enable committee members to conduct long-distance dialogue without the expense of travel.

In correspondence with the symposium director, one committee member, Joyce Ford (the representative for parents of children who are deaf-blind), articulated several concerns about the committee's direction to date. To quote from her letter:

> What we accomplished in the meeting was to identify problems. Problems of systems. Problems of families. Problems of being deaf-blind . . . . (But) in coming into this meeting, we already knew what the problems were . . . . As a parent, my hope was to have the opportunity to directly influence the future direction of the Department of Education in its provision of services to my son . . . through identification of critical educational issues . . . . The critical issues then, in my estimation, are not what we know, but what we do not know. The critical issues are not what we need to do better, but what we're not doing at all. The critical issues do not divide a person into systems that already exist, but look at systems that don't exist . . . . I really think we need to critically look at what we're not doing if we intend to address the children's needs for the next decade.

Copies of Joyce Ford's letter were distributed to planning committee members with a request for further input on symposium speakers and structure. Within several days, amidst a flurry of phone calls,

not only had the committee fully endorsed Ms. Ford's hope, but had also determined that she would be an outstanding choice for keynote speaker, to set the symposium's tone and direction.

During a second meeting of the committee, in March, 1992, the initial lists of presenters, reactors, focus group leaders, and other attendees were approved. Contact was initiated by the symposium director with each, and once their acceptance was received, they were sent a packet containing a copy of Ms. Ford's letter, a list of the topical suggestions from the planning committee, and a letter specifying tasks.

Presenters were given the following instructions:

> Your presentation shall offer a broad-based snapshot of (the topic) as it exists today. That is, treatment of the topic should be global, comprehensive, and reflective of the "state-of-the-art." Your task is not to define and illuminate for the audience all dimensions of a particular topic—but rather to succinctly capture, through a scholarly overview, the state of current practice: what is being done. Your presentation should articulate a vision for the future. Priorities to address the needs of this population will be determined in the near future. Noting this, it is incumbent on our presenters to complement their state-of-the-art message with an equally powerful vision for the future—what needs to be done.

Reactors for each topical area were given the following instructions:

> Your task as a reactor may include extending, expanding, balancing, supplementing, contradicting, or otherwise responding to the text of the presentation. Unlike the formal papers prepared by presenters, reaction papers need not include comprehensive literature reviews. Though the reaction may include citations, your central task is to consider the text of the presentation and respond/reply to the points contained therein.

Focus group leaders were given these instructions:

> After the presentation and reaction, all participants in the symposium will break into smaller sessions to discuss the presentation/reaction and generate concrete suggestions for future direction. The focus groups will follow a prescribed process aimed at maximizing participant input and generating a product. The product will **not** require any type of group consensus. Each group member will list his or her suggestions for future direction in the focal topic area. The focus group is a stimulus instrument designed to facilitate each participant's generation of suggestions. Your task as focus group leader will be to manage one hour-long session.

Lastly, at-large *participants* were invited with these instructions:

> Recognizing your leadership and involvement with children and youth who are deaf-blind. . . , your role shall be to listen to presentations and reactions, participate in focus group sessions, and generate specific suggestions for future directions.

As invitations went out to invited attendees, the process of creating an optimally accessible environment was initiated. For all constituencies to assume active roles in the symposium, it was necessary to ensure the accurate and efficient flow of communication. To this end, the following section details the development and implementation of services.

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ACCESSIBILITY AND INTERPRETER SERVICES

Richelle Hammett, Coordinator of Support Services

The following discussion covers issues addressed in preparing for and coordinating support services for the National Symposium on Children and Youth Who Are Deaf-Blind, including planning, recruitment of interpreters, and onsite coordination.

Planning

The coordinator for support services provided a crucial connection and was an active member of the planning team from the very beginning. Initially, a rough budget was developed that considered the estimated number of platform, group, and one-to-one interpreters and the length of time needed daily for interpreters, guides, and support service people. This budget included the rental of adaptive equipment such as assistive listening devices and a VersaBraille. It also included the leasing of special accommodations for the symposium site at the Ritz Carlton Hotel; namely, lighting (i.e., spot lights), and TTYs for the front desk, guest rooms, room service, and for incoming and outgoing hotel calls. Attendees who were deaf, blind, or deaf-blind were then consulted about specific interpreter needs and preferences. After defining what support services were necessary and desired, the budget was revised.

The coordinator next visited the conference location to answer questions about the symposium setting, visual background, and natural lighting. Meetings were scheduled with various hotel staff.

Recruitment of Interpreters

In addition to platform interpreters, teams of interpreters were needed to work one-on-one with participants who are deaf-blind. Strict attention was given to addressing the unique needs of each participant. The coordinator talked directly with the attendees to discuss personal preferences (interpreters who had worked with them before, interpreters who were deaf or hearing, male or female, right or left handed) and needs (language, style, communication mode, lighting, seating arrangements). The symposium setting was also discussed. Some of the topics addressed were background/backdrop, interpreter clothing color, guiding, room lighting and arrangements, and the overall hotel setting.

A list was generated of the requested interpreters who work with the deaf-blind community from the metropolitan Washington, DC area, who were available during the specified time. This planning, months in advance, proved both beneficial and necessary.

Other questions still needed to be answered. For example, how many people would be accompanied by someone who could provide support services during breaks and meals? Would the attendees be at every session or would their interpreter be available at some times to interpret for/relieve someone else? Would the participant need guiding before or after symposium hours, outside or within the hotel, or just between sessions? Awareness of these issues enabled the coordinator to address specific conference and budget needs, such as hiring the appropriate number

of interpreters (no more, no less) and avoiding employment of interpreters with skills that did not match the communication needs of the attendees. Qualified interpreters, both deaf and hearing, who were experienced with interpreting and negotiating communication with individuals who are deaf-blind were then enlisted. Contracts were drawn up, confirmation letters, speaker biographies, and copies of the keynote and presentation lectures were sent. A preconference meeting was scheduled for the interpreters (this meeting included massage therapists who donated their time and energy to work on shoulders, arms, and hands!).

An "Awareness Training and Dialogue Session" was scheduled with the hotel staff to discuss special needs and cultural differences. Emergency procedures were discussed (e.g., in case of fire or bomb threat), and questions that related to various departments were addressed (e.g., how to relate to guests who are deaf-blind in the restaurant, at the front desk, or with the concierge, and how housekeeping might deal with having numerous guests who are deaf-blind.)

Onsite Coordination

The first task was the "standard" scheduling of interpreters to work with participants and speakers in various meetings throughout the symposium and scheduling interpreters and guides for meal and break times and for use in situations that were not on the main agenda. Second, as always, there were unanticipated situations: People attended who had not requested services, some interpreters could not make it at the last minute, and unforeseen circumstances changed a request for visual interpretation into tactile interpretation. Extensive preparations were also made for emergency situations.

To summarize, the following areas received considerable attention in planning for the symposium:

- Mobility access to entire conference
- Transportation needs of all participants
- Logistics (backdrops, seating, furniture placement, distance between rooms)
- Adaptive equipment
- Lighting of all conference spaces (positioning, intensity, placement)
- Presentation format (copy of speaker notes, pace, style, agenda, specialized vocabulary, etc.)
- Interpreters (Deaf & Hearing):

  Platform

  Small group

  One-to-One

- Communication

  Mode/Style

  Language

  Preferences

  Special or Unique Conditions

The extensive preparations and attention to detail resulted in a symposium that facilitated order, communication, and safety for all participants.

♦ ♦ ♦

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EXECUTIVE SUMMARY

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EXECUTIVE SUMMARY

Overview

The Executive Summary presents abstracts of symposium papers and focus-group generated recommendations for future directions. The Executive Summary serves the reader in two ways. First, a reader interested in getting the flavor of a particular paper's recommendations for the future should glean from each abstract, a hint of the author's perspective on the future. The reader is, of course, urged to consult the full paper to appreciate the context and content. Second, a reader interested in examining focus groups' specific recommendations for the future will note that such recommendations are succinctly organized under six major headings.

The reader should note that symposium papers were delivered by 26 experts invited by the planning committee to share their perspectives and experiences. These same 26 experts also participated in the focus groups together with an additional 60 invited attendees. Focus group recommendations, then, were generated by all conference participants. How closely do the focus group recommendations mirror the papers? Papers provide supporting rationale for some focus group recommendations and details for implementation of others. In some cases, however, recommendations from focus groups were not addressed in papers, and recommendations from papers were not addressed by focus groups. For this reason, the reader wishing to gain a complete picture of the overall symposium's counsel for the future is urged to view the papers and the focus group recommendations lists as *complementary.*

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ABSTRACTS

Keynote

Presentation: Joyce Ford

We must try to develop a collective understanding of the issues of this symposium, endeavoring to view today's problems from the many different perspectives represented here. We must plan together to achieve the best possible education—the best possible life—for those who are deaf-blind.

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Early Intervention

Presentation: Deborah Chen

Effective early intervention is hampered by a shortage of well-trained professionals and the lack of individualized plans for families. A comprehensive (cross-disciplinary), coordinated, family-oriented system of early intervention is recommended. Specifically mentioned are establishing resource centers where families can receive information about available community services and programs, and giving parents (caregivers) more assistance in practicing early communication with the child. Professionals should receive cross-disciplinary training that includes knowledge of family dynamics and cultural and lifestyle expectations, knowledge of technology and alternative communication methods, and skills in working with other professionals, as well as with adults and infants. A "seamless" system should begin with early diagnosis and referral and end with true implementation of the Individualized Family Service Plan.

Reaction: Kathleen Stremel

At this time all states are participating in efforts to meet requirements of Part H of the Individuals with Disabilities Education Act; however, they are at different stages of development and implementation, and services are not standardized. Issues to address include personnel development that will incorporate multiple skills, both technical and interpersonal. We also need to provide more services in natural environments and bring about more family involvement and support. Most of all, we need to improve our intervention strategies to facilitate responsive rather than intrusive interactions. This goal can be achieved by working more closely with medical personnel to increase parental empowerment and to facilitate early identification; by facilitating support for families from other parents and parent groups; and by providing respite programs to families. Parents and professionals need to learn to work as partners with a strong local community commitment that (a) recognizes the value and potential of every child, (b) realizes the importance of the child within the family structure, and (c) recognizes the importance of the family within its community.

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Population/Demographics

Presentation: Victor Baldwin

Numbers and descriptions of the population of people who are deaf-blind are presented. An emphasis is added that the real reason for gathering this information is to ensure that the population will receive the highest quality of services (rather than to satisfy the requirements of a grant proposal). The present census is a considerable improvement over past efforts and is beginning to reflect more accurately the actual incidence of dual sensory problems in the nation's population, birth to 21. We need to learn as much as possible about this population in order to establish a national

repository of information that will include data for all ages and all levels of functioning. In addition, this data base should include a tracking system that will assist in reducing gaps in services and provide better ways to share information among programs. We need also to fund research projects that examine the uniqueness of the learning processes in persons who are deaf-blind. Results from this research should be used in personnel preparation programs and will lead to design of services that are more effective.

Reaction: Marianne Riggio

Accurately defining the population of children and youth who are deaf-blind is essential if we are to provide high quality educational services. We must therefore create a more accountable system for identification which will include screening and formal diagnostic evaluation *in conjunction with* functional assessment. A task force made up of professionals, consumers, and family members could establish such a system. The criteria by which Section 307.11 proposals are evaluated should specify how well-informed the project is about the children it proposes to serve; their process for identification; and how aligned the direct services and technical assistance are to the needs of individual children and their families. Categories of "unknown" and "not tested" should be eliminated from census forms and child count should not be a separate factor within the funding equation. With clearer knowledge about the individuals to be served under Section 307.11, high quality centers of expertise can be developed to provide information, training, advocacy, and support.

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Family Services

Presentation I: Mary O'Donnell

During 28 years of working to improve services for those who are deaf-blind we have seen much progress in quality, diversity and delivery of services; yet, too many families are inadequately served. Today's parents need the following: a team of expertly trained professionals to work in partnership with them to help them make informed decisions; support (in-home help and monetary assistance for equipment); individual choices and flexible planning; respect from professionals for the entire family unit; a suitable array of adult service choices; and an emphasis on self-determination.

Presentation II: Ralph Warner

Since parents must advocate for services for their children, they are often placed in stressful adversarial positions with professionals. Professionals need to be trained in how to work in partnerships with parents.

Presentation III: Barbara Caudill

Mainstreaming presents special problems for parents. Agencies and the public schools often are adversarial. Special equipment needed for school work is unnecessarily difficult to acquire, and academic progress is often at the expense of social relationships. Services that focus on the needs of the individual child should be available from the beginning of the educational experience.

Literature Review:
H.D. "Bud" Fredericks

The majority of the literature about parents of children who are deaf-blind appears in the early and mid-70s. The area of concern to parents that is reported most frequently and consistently from the 70s to present day is

the transition of their children from school to adulthood. On the other hand, there is a paucity of published literature about parental opinions regarding P.L. 94-142 and the Individuals with Disabilities Education Act. With one notable exception, professionals surprisingly have not focused their research efforts on the views of parents regarding the least restrictive environment concept in education and the movement to inclusion.

Reaction: Therese Rafalowski Welch

Both families and service providers need to learn how to work together. Adults who are deaf-blind and parents of children who are deaf-blind are important resources and should be enlisted to provide information and support to families, especially at the time of diagnosis. At all stages, counseling and support groups for the entire family are essential. We need training programs to teach parents how to facilitate communication among all family members. Most of all, professionals must learn to listen to families to ensure that programs are truly family centered.

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Psychosocial Services

Presentation: Harvey H. Mar

Current practices in the delivery of psychosocial services and their effectiveness in addressing certain aspects of social and emotional well-being—social relationships, management of undesired behaviors, and counseling and related mental health services—are reviewed. Recommendations are to: (a) involve community resources such as medical and mental health centers in our education and training endeavors; (b) develop integrated models of mental health assessment and care; (c) eliminate the territorial mindset that exists in psychosocial services; (d) invest money and energy toward creating better generalists (rather than specialists) among our service providers; (e) lobby our higher education institutions to better prepare psychologists, social workers, counselors, psychiatrists, and therapists; (f) support efforts by family members to educate medical, mental health, and social service professionals; (g) target the neighborhood, worksite, and other public domains as environments for our programs; and (h) develop a data base of unique issues, diagnostic concerns, and effective treatment strategies.

Reaction: Theresa B. Smith

In defining the population, we must recognize the vast differences between those who are cognitively impaired and those who are not. In general, mainstreaming tends to segregate rather than integrate and leads to mental health problems, of which the most important is lack of self-esteem. Encouragement and funding of retreats, camps, and conventions of the American Association for the Deaf-Blind will provide those who are deaf-blind with regular association with role models and "natural" peers. Professionals can learn much from observing those who are deaf-blind as they live and work in natural settings made possible by the establishment of deaf-blind communities that provide essential support and an environment that fosters self-determination. Finally, professionals must recognize the value of the ideas and expertise of members of the deaf-blind community. To foster this exchange of information, children who are deaf-blind must be taught American Sign Language, and interpreting training programs, taught by national experts, should be offered on an annual basis.

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Communication

Presentation: Robert Stillman

Historical background is presented as well as an overview of current programs for those who are deaf-blind. We need agreement on the meaning of commonly used terms, and we need to know more about factors affecting the acquisition of communication skills. Third, we need to learn more about these students to account for learning differences not readily explained by the presence of impaired vision and hearing, that is, knowledge of the cognitive strategies these students employ. We need better preparation of educators who now know little about acquisition of communication skills and even less about students who are deaf-blind. Finally, professionals need to reshape their thinking and techniques since most of these students are now in integrated settings. The goal is effective communication that will result in greater inclusion in society.

Reaction: Steven Collins

We must recognize that communication includes many aspects: facial expression, body language, and cultural rules. From the earliest ages, people who are deaf-blind must be exposed to their "natural" language. They have an internal language and a powerful need to communicate. Those established in the deaf-blind community have the ability to open the world of communication to culturally isolated deaf-blind individuals. Researchers, parents, and professionals need to build rapport with people who are deaf-blind (instead of "using" them for research purposes). They need to learn to communicate on all levels with them. Most of all, they need to listen to and learn from those who are deaf-blind, respecting their experiences and learning their "natural" language.

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Personnel Preparation

Presentation: Barbara A. B. McLetchie

We are faced with dwindling numbers of faculty and an erosion of programs, especially in the fields of low-incidence disabilities. A 1992 national survey indicates that during the next decade there will be a need for 960 new teachers of students who are deaf-blind. To meet this projected need, four areas deserve attention. First, through federal funding, we must establish innovative personnel preparation programs that include the ideas of shared internship sites, connected, rather than competitive, programs, and creative placements and cooperative follow up of graduates. These innovations will motivate young people to choose and stay in careers in this field. Second, we must recognize and prepare for the ever-expanding roles of teachers as coaches of paraprofessionals and professionals, as family interactors, and as team players. Third, we must encourage establishment of national standards—a necessary foundation for determining "best practices" and for clarifying and elevating professional identity. These standards should be incorporated into grant proposals for personnel preparation programs. Fourth, we must encourage personnel preparation programs to make meaningful and practical links with adult services. To achieve this, as part of their preparation, future teachers must have real experience with adults who are deaf-blind.

Reaction: Roseanna C. Davidson

We must develop a clear, accurate understanding of the population through better exchanges of information about numbers and etiologies. We must also develop as a profession by compiling and publishing our history and establishing a set of standards and a code of ethics. We must make a commitment (and support that

commitment with funding) to stable, cooperative pre-service professional training offered at the graduate level in strategic geographic locations. The combination of sensory impairments is the most significant feature to be addressed and calls for professional expertise to make educational and environmental modifications, especially in the area of communication.

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Educational Services

Presentation: Michael T. Collins

The National Association of State Boards of Education stated in 1992 that children classified as special education students are not achieving what they are capable of; they are not being prepared for life after school; and current mainstreaming practices are not producing their intended outcomes. Many of these problems are due to a rapid shift into decentralized services without a reasonable infrastructure in place to assist the local school systems. We must do the following: Establish a national clearinghouse with a newsletter and resource referral system; set up more meetings and training activities across state lines to ensure a fertile exchange of information; fund development of high quality training materials; fund 8-10 personnel preparation programs within universities that are in strategic geographic locations; conduct research on what methods and services work; develop within each state a network of consultant/itinerant/resource people; utilize more · paraprofessionals (similar to Canada's intervener program); develop a "quality indicators" assessment; and finally, set up an advisory committee made up of consumers and professionals in the field.

Reaction: John M. McInnes

In the province of Ontario, Canada, a program to provide services to congenitally and early adventitiously deaf-blind had the following goals: to educate and advise parents and siblings how best to deal with the child; to support the classroom teacher so he or she could provide day-to-day support; to work with therapists and other professionals to educate them; and to provide information to members of the medical profession. Specially trained consultants worked with both parents and teachers to develop a program designed to meet the needs of each child, to be delivered in the home, the community, and the school. A fundamental and very successful aspect of the overall program was the use of trained local individuals (interveners) who provided the support necessary to allow the child to function successfully in the least restrictive environment.

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Independent Living

Presentation: Bernadette M. Kappen

The overall goal of an individualized education program is to foster independent living skills, especially in the following areas: self-care/home and personal management, recreation and leisure, orientation and mobility, transportation, and technology. To improve self-care skills, we need to develop teacher training modules, promote the use of a functional curriculum approach, develop resource materials for teachers and parents, provide more support for parents, and develop a resource catalog on technical aids. In the area of recreation and leisure, training modules should be developed for use with all ages along with increased awareness of the importance of recreation. To improve orientation and mobility, materials and courses need to be developed, and electronic tactile and auditory travel devices should be improved. A special study group should be established to

study the transportation needs of this population. Finally, those who are deaf-blind need improved access to technological equipment and better awareness of its availability.

Reaction: Harry Anderson

In order to teach independent living skills to our children who are deaf-blind, we need to recognize the importance of certain qualities of life that many of us who are not disabled take for granted. We must give these people the feelings that they are loved and that we have high hopes for their futures. In addition, we must give parents and children ways to manage stress, the opportunity to develop a sense of humor, techniques for sharing responsibility, methods for seeking information, and tools for making friendships. Finally, our politicians and policy makers need to consider all aspects of this population's problems so that services will be integrated and holistic in nature.

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Adult Services

Presentation: Douglas Watson

First, the adult service system needs to be more accessible. To achieve this, we need: (a) a reliable data base on the size, distribution, and characteristics of adults who are deaf-blind; (b) better interpreter training programs; (c) technical assistance centers; and (d) improved personnel preparation programs. Second, adults should have expanded options for choice and control of services and supports. To achieve this, they must be represented on adult service advisory councils; they must participate in Individualized Written Rehabilitation Program options for choice and control; and we must develop voucher or certificate demonstration programs. Third, in order to achieve a broad systemic and holistic model of community-based services, we must facilitate inter-agency planning and cooperation. Finally, we need to develop a consumer-driven system by promoting consumer self-advocacy and involving consumers and their families in the planning and organizing of adult services.

Reaction: Stephen Perreault

Services for adults who are deaf-blind need to be more accessible as well as provide more continuity. A 1984 task force in Massachusetts examined the service needs of those who are deaf-blind and how those needs were being met. The resulting program used a system of centralized case management within a lead agency that was able to provide centralized information and referral, coordinated case management, utilization of specialty support services, and coordination of inter-agency resources. On a national level, leadership in achieving coordinated services might be provided through the Rehabilitation Services Administration (RSA). Other recommendations include improved personnel training, more choices and control of services by those who will receive them, and more inter-agency program planning and coordination. Recommendations presented in the position paper of the National Coalition on Deaf-Blindness are cited and RSA is urged to collaborate with the writers of that position paper.

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Self-Determination

Presentation: Janice Adams

Barriers to development of self-determination include lack of opportunities to practice decision-making skills, negative attitudes of others including professionals and family members, poor independent living skills, lack of information about

choices, and poor communication skills. To offset these barriers, the earliest possible intervention is recommended to provide options and allow practice in decision making. Teachers must be trained to hold positive expectations for these people and to allow them to participate in planning for their education. Education should provide access to interpreters, assistive devices, and training to improve communication skills. Children also need contact with positive role models and adult professionals who are deaf-blind. One way to achieve this is for those who are deaf-blind to attend the conventions of the American Association of the Deaf-Blind. Most of all we must work to provide emotional support to these people who may be fearful about making decisions that affect their future.

Reaction: Barbara Ryan

The components of a successful educational program include active involvement of the family from the beginning, extensive training for teachers in the area of dual sensory impairments, a language-based program with the use of individualized communication systems, a functional curriculum, and future-oriented objectives that reflect the goals of both the parents and the professionals. In addition, the medical profession needs more training and information in this field.

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Technology

Presentation: David Goldstein

The person who is deaf-blind can enjoy regular and rewarding contact with other people with the help of signaling systems, assistive listening devices, and computer-assisted communication aids. The presentation details these three areas of technology and presents a list of manufacturers, addresses, and phone numbers.

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FOCUS GROUPS: PROCESS/RECOMMENDATIONS

Symposium focus groups were designed as highly structured opportunities for groups with historically disparate levels of power and influence to join in creating a vision for the future of services to children and youth who are deaf-blind.

All invited participants (excluding federal officials) were pre-assigned by symposium staff to five different focus groups (necessarily limited because 2 of 10 topically different focus groups ran concurrently). Assignment to focus groups was determined by project staff's assessment of each participant's area of expertise, experience, and potential strength of contribution. Participants in every focus group were charged with writing, on a provided color-coded form, their *specific recommendations for future direction* relative to their group's designated content area. All participants were additionally instructed that, in the event they wished to provide recommendations on a topic other than the one to which they were assigned, the necessary forms could be obtained from the registration desk.

Symposium focus groups (each 60 minutes in length) used a process that was highly structured for two reasons. First, a structure was needed to equalize input from constituencies with historically disproportionate levels of power, political savvy, and influence (parents of children who are deaf-blind, adults who are deaf-blind, adults who are deaf, service providers, administrators, etc.). Second, given the pace and complexity of communication between participants who are deaf, deaf-blind, blind, and hearing/sighted, development of a well-defined structure was essential to facilitate dialogue and prevent chaos.

Focus group leaders were selected by the symposium planning committee for their ability to steer participants through the process. Each focus group was structured in the following manner:

1. Participants arrived and found seats in a horseshoe-shaped arrangement; interpreters were positioned.

2. Participants stated their names and offered brief descriptions of their role/agency.

3. Participants each took five minutes to "jot down" initial key ideas about future directions particular to the group's assigned content area.

4. Round 1: Using a Panasonic Vibrating Alarm (#TG475) that could be clipped onto clothing or velcro-fastened around the wrist, participants each took one pre-set minute (two minutes for participants who were deaf-blind) to present their key idea(s). The vibrating alarm was utilized to enable each individual, including people who were signing, to monitor their own time. When the alarm vibrated, signaling the end of one's time, it was passed to the next person. Except for technical/linguistic clarifications, participants were not permitted to interrupt each other during "their time."

5. Round 2: Using the alarm, participants each took one pre-set minute (two minutes for participants who were deaf-blind) to make additional comment(s) or provide clarification of ideas.

6. Participants were instructed to use the remaining group time (or in some cases the remainder of the day) to list their specific recommendations for future directions. This was *not* a consensual process. Rather, each group member was invited to list his or her personal recommendations.

All recommendations were entered into a computer and thoroughly/repeatedly analyzed by project staff and editors to delineate themes. Six organizing themes emerged and specific recommendations were listed under each theme.

The final recommendations were not edited to eliminate contradictions. Project staff did not see it as their responsibility to meld the perspectives of disparate constituencies into an artificial whole. To this end, the integrity and flavor of the aggregate of recommendations were preserved through organization in a thematically clear and readable manner.

We suggest that a transdisciplinary group be convened to suggest action on these recommendations at the federal, state, local, and family levels. Further, we suggest that three to four years from now (1996?), another symposium be commissioned to determine levels of progress on these actions and to target new issues.

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FOCUS GROUP RECOMMENDATIONS

Education

- Focus on communication as a high priority:
  - Organize a national symposium focused only on communication
  - Examine Canadian intervenor system
  - Establish interpreter performance standards and curricula
  - Develop training materials for professionals and parents about nonsymbolic communication
- Modify existing curricula:
  - Emphasize holistic (person-centered) approach
  - Emphasize functional training, personal decision making, and use of natural settings in IEPs
  - Establish retreats, summer camps, and other social/recreational opportunities
- Involve students who are deaf-blind and their teachers with adults from the deaf-blind community
- Implement a team approach to improve networking between educational, adult, transition, and other service personnel
- Set up centralized centers for early intervention services that will incorporate medical, educational, community, and other family support programs

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Personnel Preparation

- Modify university/college programs:
  - Set up university-supported interdepartment and inter-university training of prospective teachers
  - Link university programs and state and multi-state projects under Section 307.11 to develop training opportunities
  - Require that teacher preparation programs include training in language development, American Sign Language, and tactile communication
- Address personnel shortages by developing the following:
  - Teacher training programs
  - Parent-infant specialist training programs
  - Interpreter training programs
  - Paraprofessional training programs (community colleges and technical schools)
- Create inter-agency cooperation through inservice training to departments of education, departments of health, medical and related service personnel
- Incorporate parents in training programs to promote parent/professional communication

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Families

- Establish culturally respectful services, including counseling and mental health services, for families (parents and siblings)
- Provide families with training in the following:
  - Communication skills
  - Use of instructional materials
  - Effective service team membership and collaboration
  - Effective advocacy skills (child-specific and legislative)
- Improve family support services:
  - Provide monetary assistance to families for in-home (respite) support, equipment, and medical needs
  - Pass family support initiatives that address diverse family situations
- Investigate multi-agency funding for one case manager to coordinate long-term services to a family
- Provide monetary assistance to parent support organizations to enhance networking capabilities on state and national levels
- Establish local and regional support networks for specialists, families, and other support personnel (include parents, adults who are deaf-blind, and members of cultural minorities)

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Adult Services

- Encourage OSERS to fund a national interpreter training center to provide materials and technical assistance to other interpreter training programs funded by OSEP and RSA
- Provide technical assistance, training materials development, and evaluation for adult service providers and programs
- Allocate funds to adults who are deaf-blind for the following:
  - Attendance at AADB Convention
  - Leadership training programs to promote peer/self-advocacy
  - Recreational activities to mitigate isolation
  - Establishment of companionship/mentor programs
  - Postsecondary/graduate education
- Develop plans for inter-agency (including schools) cooperation with single point of entry and single-agency responsibility
- Facilitate transition and independent living:
  - Increase frequency in assessment of independent living needs/skills
  - Provide services to employers to facilitate job retention and social relationships
  - Improve access to transportation
- Establish a continuum of adult services that extends beyond transition into the adult years (e.g., Seattle Service Center Model)
- Develop mechanisms for obtaining consumer feedback on nature/quality of services including monitoring of young adults as they leave the educational system

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307.11 Grantees

- Retain the state and multi-state projects under Section 307.11; pursue an increase in funding to increase services
- Review the funding criteria for state and multi-state projects under Section 307.11 to eliminate or downplay the "child count" criteria and emphasize competence in offering services
- Develop linkages between university personnel preparation programs and state and multi-state projects under Section 307.11
- Mandate a full-time coordinator with expertise related to children who are deaf-blind for state and multi-state projects under Section 307.11
- Require states in state and multi-state projects under Section 307.11 to demonstrate their building of a system of local specialists with expertise related to children who are deaf-blind and who can be a resource to assigned regions
- Establish a national advisory committee for state and multi-state projects under Section 307.11
- Include parents in the design of priorities in the use of 307.11 state funds
- Develop regional programs that will provide more holistic service than local ones
- Fund full-time positions for coordinators of state and multi-state projects under Section 307.11
- Require state and multi-state projects under Section 307.11 to document details of family-related services that are available

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Research and Development

- Establish as a funding priority and provide specific RFPs that would focus on the following areas:
  - Assistive technology
  - Screening and assessment procedures including functional assessment
  - Sensory assessments on all special education students
  - Establishment of a National Repository of information about all those who are deaf-blind
  - Development of evaluation strategies to determine program effectiveness (inclusion vs. segregation, consumer satisfaction, etc.)
  - Language and communication
- Fund model demonstration projects (3 years + outreach):
  - Demonstrate community inter-agency cooperation
  - Develop "best practices" in the following areas:

    Early intervention (with Maternal and Child Health) programs

    Elementary programs

    Secondary and transition programs

    Young adult programs, especially in working and living arrangements
  - Define, describe, and develop projects that focus on family issues
  - Demonstrate the efficacy and effectiveness of distance education programs
- Fund a national symposium on the issues related to adult services

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PROCEEDINGS

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KEYNOTE

BEYOND TYPICAL THINKING, BEYOND TODAY

Joyce Ford

Abstract: We must try to develop a collective understanding of the issues of this symposium, endeavoring to view today's problems from the many different perspectives represented here. We must plan together to achieve the best possible education—the best possible life—for those who are deaf-blind.

Last November the planning committee of this symposium met to identify the topical areas of presentation, to identify who the candidates for such presentations might be, and to define what would take place today and tomorrow. I must tell you that I was in very good company to accomplish that task.

Over the past year, you have received some correspondence which outlines the scope of our responsibility and so I will not dwell on our mission for these next two days. Still, I think it might be helpful if we re-examine the overall objectives and the direction we should consider taking in order to accomplish those objectives.

This Request for Proposal (RFP) called for us, collectively, to identify 10 critical issues as they relate to education of children who are deaf-blind. It called for presentations and reactions on these issues and for the final proceedings of this symposium to be assembled and disseminated. This is certainly not the largest project to have ever been funded, nor is it the one that has been given the greatest amount of time. Still, in my estimation, it is an extremely unique opportunity to effect positive change in the educational system for children.

My nine-year-old son is deaf-blind and I am very involved in his education. However, I am not a professional educator, nor am I deaf-blind. My perspective is but one aspect of the entire picture, and so it is important that the membership of the symposium reflects other aspects as well.

Following the planning committee meeting last year, I had some concerns which I expressed in a letter to John Reiman, the symposium director. Since I never seem to be short of words, you have probably guessed that it was a lengthy letter!

What resulted from that correspondence is what you see before you now, a long-letter-writing parent giving the keynote address! I can only surmise that this resulted because the concerns I expressed have some level of validity and that the manner in which I presented them left some sense of optimism for this symposium to accomplish its task in the best possible way.

I want to share some of what I wrote to John that day and to discuss some of my reasons for those concerns. I must preface this discussion with a touch of history about myself. Since Riley's birth, I have been labeled with an abundance of adjectives. I have been called "unresponsive," "overprotective," "impractical," and "unreasonable." I have, of late, been able to add "idealistic," "unrealistic," and "too theoretical" to that list. Now, it may very well be that I am all those things. However, I do hope that you will at least agree to hear my concerns before you cast your decision

or add another adjective to my ever-growing list!

In my letter to John, I first discussed my concern regarding the difference between problems and issues. At times, I think we get trapped in our own thought processes, and because of that, we don't challenge ourselves to think in new ways, to be as creative as we might be, or to conceptualize possibilities beyond those ideas that we know to be sound and true. What I will propose to you in this presentation is that we attempt to release ourselves from the confines of "typical" thinking—to step away from our stimulus-response patterns of thought, and to begin to formulate our ideas collectively in terms of outcomes.

I'd like to suggest that we do an exercise together that captures the feeling of what I'm talking about when I speak of outcomes and the thought process necessary to reach those. It's a simple exercise that you can do in your head. Think in terms of a list of three things. Create a mental picture of your list and the numbers 1, 2, and 3. Now, I want you to list three positive outcomes that would occur if you were to drop dead at this very moment.

I have to tell you that when I first did this exercise, I was so tremendously bright that I was the first one to finish and raised my hand immediately! My list said:

1. I can sleep in every day.

2. I don't have to watch what I eat.

3. This pretty much solves the worry about growing old.

Unfortunately, those were not the right answers! The exercise went on to say that these outcomes must be for *others* who are close to you. List three positive outcomes *for others* if you were to die at this very moment.

If you're having difficulty with this exercise, it is most likely because we have not learned how to think in these terms. We are not accustomed to taking what we believe to be an impeding negative and looking beyond that for positive outcomes. We do not traditionally use our brains in that manner, and so we seldom apply that kind of thinking in our day-to-day lives.

When I did the exercise again, I was able to come up with two valid outcomes in my list of three. The first two were, of course, very personal. The third one was that the dog would be allowed to sleep on the bed, something which he has always wanted to do! Perhaps I'm not as bright as I first thought I was, but I figured two out of three wasn't so bad after all!

I chose to use this exercise because it reflects two areas of my life: (a) The "world at large" generally has a negative view of our family circumstances, and (b) it is this kind of negativity that we are constantly attempting to overcome in our day-to-day lives. For me, survival is a matter of having the ability to think differently.

Applying that kind of thinking to the task before us, it is important to recognize that there *is* a difference between problems and issues. It is equally important to recognize problems in order to identify issues. Our work during these next two days will identify both problems and issues around education for children and result in recommendations for constructive changes within the educational system. I hope we will keep in mind that the outcomes we seek affect lives well beyond the educational years. People, both children and adults, are unique individuals, and we cannot and should not make general or blanket statements about them. It is important to

remember that individuals influence system change and that systems need to respond to those individuals.

For those reasons, I was concerned that once again people who are deaf-blind would be divided into the two service systems that currently exist: educational services and adult services. All too often, these systems translate into being entitled to everything and getting nothing, or being entitled to nothing and receiving nothing. Now I know that this doesn't come as a news flash to most of you here. Additionally, I'm not here to throw water on the remarkable strides that have occurred in response to this disability. What I will say, however, is that the list of problems is incredibly long. The very identification of multiple problems is our most solid indicator that positive change is needed.

I want to share a paragraph from my letter to John about this concept and how I saw my role on the committee:

As a parent, my hope was to have the opportunity to directly influence the future direction of the Department of Education in its provision of services to my son, other children like my son, and the families who live with children who are deaf-blind. That is how I defined my "role" as parent representative. I had hoped that the other individuals would also bring to the meeting their own "role" in their representation, their own desires to influence the Department of Education, and that the result of these collective roles and influences would be the identification of critical educational issues that stand between children's lives as children and their lives as adults functioning within our society. The critical issues then, in my estimation, are not what we know, but what we do not know. The critical issues are not what we need to do better, but what we're not doing at all. The critical issues do not divide a person into systems that already exist, but look at systems that don't exist. This was my expectation for the group.

I can tell you that my hopes for this group are no less than my hopes were for the planning committee. Each of you has a "role" to play in these proceedings. Each of you also has influences to bring. I will ask you to set aside your agendas, philosophies, and differences and open your minds to a new way of thinking—thinking that addresses people in the context of their whole lives. I am not asking you to compromise your values. I am asking you to bring your values into partnership with the others in this room to effect constructive system change for children who are deaf-blind, for the families who live with children who are deaf-blind, and for the professionals who deliver services to individuals and families.

I remember hearing a story of three people who are blind-folded and asked to examine an elephant. The first person touches only the elephant's trunk and then confidently describes the beast as a great snakelike creature, similar to a python. The second person feels only the ears and announces that it is a bird that can soar to great heights. The third individual examines only the elephant's fringe-tipped tail and reports of an animal that is strangely similar to a bottle brush. So it is with any experience. Each individual perceives it in a different way and takes from it a different lesson.

Each person obviously felt competent enough to describe the animal. No doubt, they would modify their views if they were to share their findings with the others. This is the idea that I ask you employ: to view the issues not merely from one perspective, but as shared perspectives. Our perspectives, as partners, will allow us to achieve our goals. Adhering to disjointed views can only defeat our purpose.

I am fortunate to have been chosen to deliver this message. For too long, parents and families have had little voice in the way services are delivered to their children. Parents have an important perspective to bring. I often worry that someone might generalize my statements or opinions to all parents and families. That, of course, is not my intention. Still, it is important for parents to have a voice. If I am able to accomplish anything, I hope that it will be to give families the voice they so deserve and that this voice will affect the services that touch the lives of their sons and daughters.

As I prepared this presentation, I realized that our life with Riley mirrors the topical areas which were selected through the Symposium Planning Committee. Because of that, I believe that my problems and issues as a parent are the very same problems and issues of the symposium. It is immensely important to me that this symposium will successfully identify those issues. If a symposium such as this occurs once every decade, then the next one will occur when Riley is 19. Riley will have nearly completed his years in the educational system by then. You can understand then, that this is a once-in-a-lifetime opportunity for me.

Let me share some of my life with you. Those of you who attended the Hilton/Perkins National Conference heard some of the trials of my life following my son's premature birth as well as our encounters with early intervention, preschool, and early school life. The 20-minute presentation only touched on some of the events our family has survived.

At one time, Riley was not identified as being deaf-blind. What this meant to our family and to Riley was that we were not able to know what to do, how to do it, or why we needed to do it. We were completely alone, not for a few weeks, and not for a couple of months. We were alone for three years. Because we were alone, our decisions were not always wise ones. We often accepted the decisions of others who we believed were more knowledgeable and competent than we. The sad reality was that most often they knew less than we did, and Riley was the one to pay the price. A natural result of those experiences was our diminished trust in the professionals who were our only allies at that time.

Rebuilding that trust has been a most difficult aspect of life for us, and it is for other parents as well. Too often our children have suffered at the very moment we become comfortable with what we have acquired. As parents, we very quickly learn that we must constantly be uncomfortable and on guard if our children are to receive the services they require and deserve. When families are placed under this constant stress, every problem becomes an issue. Likewise, every issue drives a family further from the services they are most in need of. I know this to be true. I live it every day.

Having the ability to think in different terms has given me the opportunity to build partnerships among the systems. These partnerships allow me safely to share my discomfort, to think creatively, and to resolve problems before they become issues. Certainly these partnerships offer me a great deal of personal support. A major outcome of that process is the kind of direct services that Riley receives. The shared thinking among those partnerships has proven itself time and again to be an essential ingredient in Riley's education, his life at home, and, most likely, will affect his life as an adult within the community.

I used an example in my letter to John which directly relates to this topic. A few years ago my son had to have his eyes surgically removed. This resulted from an unwise choice we made during Riley's

infancy based upon the advice of a trusted physician. We did not expect repercussions from that very early decision years later in Riley's life, and I had a great deal of difficulty watching my little boy pay the price for that choice.

Riley has always had trouble with his sleep patterns and surgery only adds to that difficulty. It was no different following these surgeries. What was different however, was that no matter what we tried or whose advice we followed, we were unsuccessful in switching his days and nights back around. Weeks passed, then months, then a year, and more. He was frequently ill and missing school. My husband and I were taking turns trying to care for him. We were at the point of exhaustion. Every illness set us back further on the time schedule.

I was beginning to travel then, and my advocacy efforts would take me away from home. In some respects that was good. Often it was the only time I had the opportunity to sleep through the night. In other respects it was not so good. My husband was left trying to juggle his job, our daughter, and, of course, all of the difficulties that Riley was experiencing. Needless to say, our family relationships were jeopardized.

Eventually, the difficulties became so great I could not sleep, at home or away. The only logical solution that seemed to remain was to begin to look seriously at placement for Riley outside our home—his home—and that thought went against every value I had for him and his future. Still, I was watching my family, myself, and our relationships collapse because of the situation we were in.

What in this example is the critical issue? Is it the lack of respite providers? Is it the lack of informed medical personnel? Is it their inability to share knowledge with parents? Is it a lack of reasonable placement alternatives?

I don't think it is any of those, although they are all valid problems and, without question, things we need to improve. The critical issue was that, as a family, we did not have access to support—the support we needed to maintain Riley in his home under extreme circumstances. There was no support system in place for us.

Once I recognized the issue I was able to join others to begin to advocate for change. Personal care services evolved in our state shortly thereafter. Should similar circumstances occur again, our family will have access to the support we need. Fortunately, many other families will be able to access that support as well.

What is important to me is knowing that this change occurred because people were willing to think beyond what *was*. We came together to look at what *could be,* and the outcome of that is what *is*. This is our task: to venture beyond the limits of today.

Some things we know. We know that you can never go back to what was. My mother taught me that lesson. She gave me a suitcase for graduation and said, "Get out and don't come back!" She didn't really say that! But she did teach me that lesson. She taught me that life is a series of changes and, as reluctant as we human beings are to accept it, change is a natural outcome of living.

Freeing our minds to dream creates the opportunity to change, to become better people, to live more fulfilled lives. We want those things for ourselves and for the people we care about. As a parent, I want those same things for my son.

I hope that as we proceed through this symposium you will keep your dreams for

children who are deaf-blind in mind. We have the ability to focus our thoughts on problems. Or we can focus on outcomes. It is our desires for the future that enable us to identify the barriers we need to overcome.

The Department of Education identified two problems in its RFP for this symposium. One was that children who are deaf-blind are not receiving services that would be considered "best practice." The other is that students who are deaf-blind are not being integrated with their nondisabled peers. I cannot emphasize enough the importance of both of these concerns. I hope that we will keep them central in our dreams throughout our time together.

A year ago, I wrote about a dream for my son. Part of that dream was that he would be included in the lives of other children, that these children would learn to recognize his strengths and in turn help to enhance his abilities. That dream became a reality last March when Riley's placement changed from a self-contained classroom to a regular third grade classroom. This is not without problems; there have been many struggles. There have been many obstacles, and I expect that there will be many more. Complex issues have arisen that concern attitudes, roles, and directions. Those too will be addressed. They must be addressed. We cannot go back to what was. My commitment to Riley will not allow me to accept less than he deserves.

My dream has many components for Riley: I want him to have choices, communication, independence, mobility, and relationships. It has components for others as well: well-prepared school staff, smooth transitions, effective teamwork, and commitment. It has components for our family: Riley's independence as an adult, his self-esteem, and our ability to have connected relationships rather than dependent ones. My dream embraces the changes that are natural to life, and are important to each of us. My dream reflects our ideals.

What are *your* ideals? What are *your* dreams for these children's educational futures and their lives beyond that? What do you say and do each day that supports your ideals? In times of discouragement have you ever found yourself saying, "If only they would look. If only they would listen. If only *they* would respond." Our challenge is that we cannot continue to preach our ideals unless *we* are willing to respond. And because we have been asked to come together to share our values and ideals, you and I, here and now, are part of the system. We are at one with those who work within the system.

As I mentioned earlier, this symposium is a once-in-a-lifetime opportunity for my son and for me to be involved in helping to create the educational framework for the next decade. In a sense, with changes in careers, new directions, and new ambitions, it may be a once-in-a-lifetime opportunity for you as well.

The astronomer anticipates the arrival of the comet. He will have only one chance to view it in his lifetime. He prepares his instruments and waits impatiently. He is anxious to take advantage of that rare event. How discouraged he becomes when the skies are filled with clouds and his chance is stolen by circumstances beyond his control.

Yes, I am idealistic. Unrealistic? Optimistic. Our task is not a small one. Open your minds and clear the skies. Look around you. *We* have become *they* for the next decade. How will we be referred to?

I wish you all success.

♦ ♦ ♦

EARLY INTERVENTION: PRESENTATION

Deborah Chen

Abstract: Effective early intervention is hampered by a shortage of well-trained professionals and the lack of individualized plans for families. A comprehensive (cross-disciplinary), coordinated, family-oriented system of early intervention is recommended. Specifically mentioned are establishing resource centers where families can receive information about available community services and programs, and giving parents (caregivers) more assistance in practicing early communication with the child. Professionals should receive cross-disciplinary training that includes knowledge of family dynamics and cultural and lifestyle expectations, knowledge of technology and alternative communication methods, and skills in working with other professionals, as well as with adults and infants. A "seamless" system should begin with early diagnosis and referral and end with true implementation of the Individualized Family Service Plan.

In preparing for this presentation, I had great difficulty in deciding how to begin. Should we be optimistic or pessimistic about early intervention services? This is a time of tremendous opportunity and also a time of crises.

Newspaper headlines are daily reminders of severe economic conditions, hardships confronting families, and the desperate situations of many infants in our country. Every month, an average of 56 thousand children are abused, neglected, or both. Every month close to 41 thousand teenage girls have babies. Every month 21 thousand infants are born to mothers with inadequate prenatal care. The number of low-birthweight infants has increased significantly in the last 10 years. Low birthweight is the leading cause of infant mortality in this country and is connected to a higher incidence of disabilities. Every month, more than 39 thousand children are born into poverty. More than 12 million of our children, one out of five, are poor. And every night, 100 thousand children go to sleep homeless. During this 30-minute presentation, 51 babies will be born into poverty (Children's Defense Fund, 1991).

Early intervention services are not isolated from our contemporary social problems. Poverty, homelessness, adolescent pregnancies, and dysfunctional family situations demand different types of early intervention services and new ways of serving families (Hanson & Lynch, 1992). The problems are overwhelming, and the needs are urgent.

This sounds very bleak, but there is good news. Through federal legislation, we have a national commitment to comprehensive, coordinated, family-focused services to infants and toddlers with disabilities and their families. There have been dramatic increases in early intervention services along with greater social acceptance of people with disabilities.

The year 1986 was a landmark year. Congress passed P.L. 99-457 amending the Individuals with Disabilities Education Act (IDEA) to include infants and toddlers with disabilities and their families, under Part H. Congress also established a phase-in period to allow states sufficient time to meet federal requirements. Although the Part H program was discretionary, all 50 states have initiated

the development of a comprehensive, coordinated, multidisciplinary, and inter-agency system of early intervention (Thiele & Hamilton, 1991). This has revolutionized the way we provide early intervention services.

Prior to P.L. 99-457, early intervention programs too often excluded parents from fundamental decisions concerning the infant, and viewed the infant's disabilities in isolation from the rest of the family. The emphasis now is on families and family-professional partnerships.

A supportive, responsive, and stable caregiving environment is crucial for an infant's emotional well-being (Goldberg, 1977; Sameroff, 1983). However, the diagnosis of an infant's disability can have devastating emotional, social, and financial effects on even the most stable family. The initial reaction is naturally one of confusion, hopelessness, and often guilt. At such times, the most basic and important intervention may simply be empathy and understanding. Thereafter, our goal must be to provide services that restore and strengthen the family.

P.L. 99-457 requires collaboration among specialists from various disciplines and different agencies providing early intervention services. This is not easily done. Think of the parents of a baby who is deaf-blind spending heartbreaking months going from the pediatrician, to the neurologist, to the ophthalmologist, to the ear, nose and throat specialist, and to the audiologist, without ever getting any practical assistance on how to help their baby's development. Finally, they are referred to early intervention services only to have an onslaught of visits from a social worker, a physical therapist, a teacher of deaf children, a teacher of blind children, an infant development specialist, and a speech and language therapist. Each of these professionals is from a different agency. Each has a different agenda, a set of forms, and a list of questions. Each is working on a different "part" of the baby. Tell me, how does this strengthen and restore a family?

Now you can understand the crucial need for inter-agency coordination at the state, local community, and program levels (Harbin & McNulty, 1990; Lowenthal, 1992) and for transdisciplinary teaming (Woodruff & McGonigel, 1988) at the program level. Developing an early intervention team of professionals from various disciplines is a cost-effective, efficient, and comprehensive approach to providing early intervention services. Currently, programs use one of three types of team models: multidisciplinary and interdisciplinary, which are both identified under Part H, and the most recently evolved, transdisciplinary (Woodruff & McGonigel, 1988). In the traditional multidisciplinary model, professionals from different disciplines conduct individual assessments, and develop and implement specialized interventions separately. This is the least effective way to promote true family-focused interventions, inter-agency collaboration, and to integrate interventions within the context of family and community activities.

In the interdisciplinary model, professionals conduct individual assessments, share information, develop interventions jointly, and then implement individual discipline-specific interventions. This model is a movement towards family-professional partnerships, integrated interventions, and community-based services.

Since the passage of P.L. 99-457, the trend has been toward the transdisciplinary model. In this approach, team members conduct joint assessments and share expertise and roles in developing and implementing interventions. Most important, parents are part of the team, and through a primary

service provider, intervention strategies are integrated into the infant's everyday activities within the context of family and community. Although an ideal, the transdisciplinary model is the most difficult to achieve because of attitudinal, logistical, and other practical obstacles. These difficulties emphasize the need for a highly skilled service coordinator to facilitate communication between team members and cooperating agencies.

As required under Part H of P.L. 99-457, the Individualized Family Service Plan (IFSP) identifies services that will promote the infant's development and the family's capacity for meeting the infant's special needs. In particular, it describes the family's resources, priorities, and concerns related to promoting the infant's development; particular early intervention services which are essential for meeting infant and family needs; and a service coordinator who is qualified to implement and coordinate the IFSP. By means of the IFSP, early intervention programs can implement family-focused services through family-professional partnerships, transdisciplinary teaming, and inter-agency cooperation (Dunst, Johanson, Trivette & Hamby, 1991).

Critical Issues

I will now highlight five critical issues in developing and providing highly individualized, community-based services for infants with disabilities and their families.

The first issue involves the nationwide shortage of trained professionals in early intervention (Bruder, Klosowski, & Daguio, 1991). A recent study in California (Hanson, 1990) found that between 52% and 83% of professionals in various disciplines providing early intervention services had received no specific training in working with infants and families. Reported training needs included field work experiences, transdisciplinary teaming, working with families, and multicultural competencies.

All early intervention service providers need specialized skills. Working with infants and their families is not at all like working with school aged children. A primary difference involves the development of an intimate relationship during a most difficult time for families. Early intervention service providers need not only specific knowledge and skills regarding infant development, but even more important, the interpersonal skills to develop a relationship of trust and mutual respect with families.

Parents need professionals who can understand their particular circumstances, listen to their concerns in a nonjudgmental manner, and assist them in creating solutions that "fit" their families. More than half of our children in the United States are so called "minorities," and early intervention service providers do not reflect this linguistic and cultural diversity. Most professionals in early intervention come from white, middle class backgrounds (Hanson, 1990) while many infants and families do not. We need early intervention services which are sensitive to the cultural and linguistic diversity of families. We need program staff who are culturally competent, and we need individuals from underrepresented groups as early intervention team members (Hanson & Lynch, 1992).

Early intervention service providers require two sets of professional competencies, one to work with infants and the other to work with adults. Working collaboratively with families requires specific skills in teaching and interacting with adults (LeLaurin, 1992). Similarly, participating on transdisciplinary teams requires special skills in communication, negotiation, problem

solving, modeling, instructional coaching, and role release.

When working with infants who are deaf-blind and their families, early intervention service providers need additional professional competencies. Infants with dual sensory impairments include infants who are hard of hearing and blind, infants who are deaf and low vision, infants who are hard of hearing and low vision, infants who are profoundly deaf and totally blind, and infants who have additional medical complications, physical disabilities, or severe developmental delays.

The unique learning needs of infants who are deaf-blind (Freeman, 1985; Jurgens, 1977; McGinnes & Treffrey, 1982; Michael & Paul, 1991) and the specific concerns of their families are not always addressed in most early intervention or personnel preparation programs (Fredericks & Baldwin, 1987; Michael & Paul, 1991).

However, infants who are deaf-blind and their families need highly individualized services as early as possible. A baby's development will be severely affected by loss of vision and hearing even when the baby has no other disabilities. Parents and caregivers may need support to develop an emotional bond with their infant. They need practical ways to promote the infant's development, such as encouraging communication by reading the baby's body signals, using tactile cues, and adapting manual signs. They may require assistance in learning to handle the devices that their babies need, such as hearing aids, contact lenses, or prosthetic eyes. They also need support in negotiating the maze of medical, educational, and other human service systems that are suddenly part of their lives.

The second issue is concerned with where early intervention services are provided. Although we lack comprehensive data, field experience tells us that infants who are deaf-blind and their families receive services in many different ways, in programs for deaf and hard-of-hearing infants, in programs for infants with visual impairments, in generic programs for infants with a range of disabilities, and only rarely in settings with typically developing peers.

The IFSP requires a statement regarding so-called "natural environments." We know that infants with disabilities benefit from participation in a variety of everyday community settings; particularly in places where typically developing infants spend their time: at home, in day care, nursery school, and community play groups (Chen, Hanline, & Friedman, 1989; Friedman, 1989). Places that are "natural" for a particular infant will depend on the child's age, culture, community, and family preference. Again, we need early intervention services which are tailored to meet the special needs of individual infants and their families.

The third issue concerns family involvement. Research and clinical practice indicates that family involvement in early intervention activities promotes infant development (Meisels, 1992). After all, we now believe in family-focused services. However, some parents may not be able to or want to participate actively in their infant's early intervention program (Turnbull & Turnbull, 1990). Requiring family participation in early intervention programs may impose day care- and job-related difficulties (LeLaurin, 1992), and even cause emotional stress or conflicts in cultural values among some families. The amount of parent involvement needs to be a highly individualized aspect of an early intervention program.

The fourth issue involves the types of stimulation used in early intervention programs. Infants learn through stimulation that is dependent on or controlled by their

behaviors—contingent stimulation (Spence, 1991). When caregiving environments are responsive, infants discover quickly that they can make things happen. To learn, infants need to act rather than be acted upon. Sensory stimulation without an infant's active participation does not promote learning. For many infants who are deaf-blind, we need to create responsive caregiving environments and powerful yet highly individualized ways to use contingent stimulation in natural settings.

The final critical issue involves the need for innovative early intervention models to handle changing demographics and contemporary social problems. Consider providing early intervention services within the framework of Maslow's Hierarchy of Needs (1970). Families cannot realistically be expected to attend to the special developmental needs of an infant with disabilities until the basic survival requirements of food and shelter are met. Only after these basic needs are satisfied can families focus their energies on the human needs for love, acceptance, and developing emotional bonds. Through feeling loved and a sense of belonging, families develop self-esteem and acquire approval and self-competence. To be effective, early intervention services have to be developed and implemented within the context of family as well as in relationship to the larger community. Families need highly individualized services from a single community-based resource to meet their priorities and concerns. This is possible through a coordinated, comprehensive early intervention system involving social service, health, and educational agencies.

Future Directions

To focus our attention on future directions in providing high quality services to infants who are deaf-blind and their families, let us consider the following eight questions and suggested possibilities:

1. What program models are needed to provide coordinated, comprehensive, family-focused, transdisciplinary, inter-agency early intervention services to infants who are deaf-blind and their families? Consider the possibility of a neighborhood family resource center, "one-stop shopping" if you will, where families could receive information about available community services and programs. At this resource center, families could submit one family history report, one set of infant assessments and one set of applications to receive referrals to health, social services, and educational agencies as appropriate. The family would select a service coordinator whose responsibility is to assist by accessing, coordinating, and monitoring services.

2. What kinds of early intervention services support caregiving environments of infants who are deaf-blind? We need to review our current program philosophies and practices. Do our services increase the infant's attachment to primary caregivers? Do our practices enhance the caregiver's emotional bond to the infant? We have research that supports programs enhancing parent-infant interaction, early turn-taking or reciprocity with infants. Specifically, trained early interventionists could assist caregivers in reading the infant's signals, developing an early communication system, and responding to the baby's behaviors. Some parents of infants who are deaf-blind need special assistance in establishing this early communication and in encouraging their infant's responsiveness.

3. What kinds of family supports are needed? An obvious way to answer this question is to ask families what they need in order to support an infant's development.

Some families need practical suggestions for caregiving routines. Other parents need opportunities to rest and refuel—to have a good night's sleep.

Another approach would be to focus on what particular outcomes are desired by individual families. What does a particular family need to be able to function as a family and encourage the infant's special development? In general, families often benefit from establishing formal and informal supports in developing coping and parenting skills. A more comprehensive approach might use a Family Systems model (Turnbull & Turnbull, 1990) to develop supports for assisting families in meeting their many responsibilities, including tasks related to economics, daily care, recreation, socialization, affection, and educational/vocational needs.

4. What training is needed across disciplines to provide high quality services to infants who are deaf-blind and their families? Cross-disciplinary training is an effective means for developing effective skills in transdisciplinary teaming. Recent research has identified inservice and pre-service training needs across disciplines serving infants with disabilities and their families. Needed professional competencies include knowledge of family dynamics, skills in working with families from diverse cultures and lifestyles, abilities to participate as an effective transdisciplinary team member, and skills for working with infants and adults. Teams serving infants who are deaf-blind and their families need a team member who has expertise in the area of deaf-blindness. We need to recruit and train early interventionists who will have indepth knowledge and skills in working with infants who are deaf-blind and their families. We also need training models which include fieldwork experience, clinical supervision, distance education methods, mentor relationships, and cross-disciplinary training.

5. What training do service providers need to support the participation of infants who are deaf-blind in a variety of community settings? Service providers need specific training in many areas, including working with families, alternative communication methods, use of hearing aids and other prosthetic equipment, ways to promote social interaction between children, and specific strategies to support participation of an infant who is deaf-blind. Training content should be derived from ecological assessments. Initially, we need information about expectations in community settings. What happens in various environments with typically developing infants? Then, for each infant who is deaf-blind, we can identify individual strengths which would enable successful participation, and specific strategies to enhance participation through physical assistance, appropriate materials, and other adaptations and supports.

6. What kinds of training will provide early intervention service providers with the professional competencies necessary to meet the specialized needs of infants who are deaf-blind and their families? Professional organizations have developed competencies for early interventionists serving infants with visual impairments, deaf infants, and other infants with disabilities and their families. There is literature that recommends specific skills and knowledge for early interventionists serving infants who are deaf blind. We need to identify the core competencies that all early interventionists need and the specialized skills needed by those working with infants who are deaf-blind and their families. There is a need for early interventionists who have indepth knowledge and refined skills in developing programs for a heterogeneous group of

infants who are deaf-blind. These resource people can then provide consultation and training for assistants, day-care providers, infant development specialists, and other early intervention service providers in a range of community settings.

7. What is the ideal early intervention service system in a world of unlimited resources? In an ideal system, early intervention services would begin with prevention, specifically with adequate prenatal and health care. Families of high risk infants would receive follow-along support and have easy access to a neighborhood family resource center. This family resource center would have a menu of highly individualized services which are integrated into community programs. Each family could select a highly skilled, sensitive, and warm service coordinator who spoke their language, understood their culture, and was able to provide personal attention because of a low caseload. Infants and families would receive the specialized services they needed in settings with typical peers from competent, culturally sensitive professionals. Transdisciplinary teams would be able to meet as needed, to share expertise freely, and to work effectively as cohesive teams.

8. What are our early intervention priorities in the real world of limited budgets and resources? Let us focus on developing safety net models which will provide a seamless system from early diagnosis and referral to true implementation of the Individualized Family Service Plan (IFSP). In collaboration with families, we can identify desired outcomes and create individualized high quality services from existing resources.

We have models of "best practices" in early intervention. Typically, these services are university-affiliated or model demonstration projects. One of our priorities should be to generalize these "best practices" into routine and natural practices of ordinary, everyday programs.

As we approach 1993, early intervention is a dynamic, evolving, and complex process, the successful result of state and national efforts. The year 1993 also marks the end of the phase-in period for Part H of P.L. 99-457. States must decide whether they will continue their commitment to a coordinated system of early intervention services. The future of infants with disabilities and their families is at the heart of this decision. The challenges are great, but the benefits are priceless.

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EARLY INTERVENTION: REACTION

Kathleen Stremel

Abstract: At this time all states are participating in efforts to meet requirements of Part H of the Individuals with Disabilities Education Act; however, they are at different stages of development and implementation, and services are not standardized. Issues to address include personnel development that will incorporate multiple skills, both technical and interpersonal. We also need to provide more services in natural environments and bring about more family involvement and support. Most of all, we need to improve our intervention strategies to facilitate responsive rather than intrusive interactions. This goal can be achieved by working more closely with medical personnel to increase parental empowerment and to facilitate early identification; by facilitating support for families from other parents and parent groups; and by providing respite programs to families. Parents and professionals need to learn to work as partners with a strong local community commitment that (a) recognizes the value and potential of every child, (b) realizes the importance of the child within the family structure, and (c) recognizes the importance of the family within its community.

In reacting to the topic of early intervention, I am unsure if I am more optimistic or less optimistic than Deborah. Many of the states that are currently in the fourth and fifth year of participation under Part H of the Individuals with Disabilities Education Act would probably not agree that we have a "national commitment" to comprehensive, coordinated, family-focused intervention for infants/toddlers and their families. Granted, Part H has provided a "strong national incentive" for individual states to make major reforms in both the provision and financing of services for infants and toddlers with disabilities. This legislation requires transforming a fragmented, and often inaccessible, collection of services into statewide early intervention services.

Whereas all states are currently participating in efforts to meet this legislation (at least until October, 1993), the states are at different stages in policy development, policy approval, and policy application of the 14 required components (Harbin, Gallagher, & Batista, 1992). These authors report that, at the state level, minimal progress has been made in assigning financial responsibility, timely reimbursement, administration and monitoring, developing inter-agency agreements, and in comprehensive personnel development. What does this currently mean for families of infants and toddlers who are deaf-blind? Basically, it means that a family that moves from Michigan to Alabama will not receive a similar level of early intervention services. There is not only a large discrepancy in services for all infants and toddlers with disabilities across states, there is also inequity of services within states. Therefore, there must be both a "local community and state commitment" to the provision of comprehensive, coordinated, inter-agency, early intervention services.

Deborah provided an excellent overview of the critical issues and future directions for young children with disabilities, including those who are deaf-blind. I would like to expand upon those critical issues and future directions, specific to infants, toddlers, and

preschoolers who are deaf-blind and their families.

Critical Issues

Comprehensive Personnel Development

When Congress approved P.L. 99-457 in 1986, it acknowledged that the greatest barrier to successful implementation would be a lack of qualified professionals to train service providers and ensure a high standard of child and family support. Development of early childhood professionals constitutes one of the largest areas of need nationwide. Additionally, Collins (1992) has pointed out that funding cuts over the past decade have resulted in fewer university programs training personnel to work with children who are deaf-blind. Therefore, not only is there a shortage of service providers trained to work with infants and families, there are even fewer early interventionists trained to work with infants who are deaf-blind. Deborah aptly pointed out that major competencies must include two sets of skills; one to work with infants, and one to work with adults. I propose that four major sets of competencies are essential for providing comprehensive services. These sets of competencies would include the following:

- Knowledge and skills to integrate multiple skills (auditory, visual, motor, communication, medical procedures, socio-affective, and adaptive skills) into caregiving routines and activities directly with the infant and young child, and to organize adaptive physical and social resources to each child and family (Appell, 1987; Walker & Kershman, 1981).

- Knowledge and skills to interact and systematically work with families, with knowledge of cultural diversity and cultural competencies. These skills should include working with siblings, dads, extended family, and other caregivers if the families desire. Possibly some of the most important skills are actually the simplest to implement, but the hardest to learn. These include listening, sensitivity, flexibility, learning from families, and admission of lack of knowledge.

- Knowledge and skills in group dynamics, coordination, cooperation, role extension, role expansion, role release, and effective "coaching" in order to work effectively with parents and professionals as part of transdisciplinary teams.

- Knowledge and skills of adult learning styles and effective teaching strategies for paraprofessionals, interveners, and day-care staff. Harbin and others (1992) point out that day care is not one of the 10 areas of professional development noted in the law, but is a key element if programs use day-care settings as one of the "least restrictive environment" placements.

Use of Natural Environments

The provision of early intervention services in the home, in day-care, nursery school, and community settings will require new skills and role changes on the part of the interventionist. Families may request that services be provided on some level in a number of "natural environments." Successful integration will require "systems change enacted through community resource networks" (Kontos & File, 1992, p. 179). Early intervention programs and service providers can assist in providing training to multiple caregivers and interacters by providing intervention services in multiple environments and through the use of videotapes.

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Although data are not available, it is probably safe to assume that very few infants and young children who are deaf-blind are receiving services in environments with typical peers. Additional models and data that focus on family-desired and child-change outcomes with this population need to be explored (Peck, Odom, & Bricker, 1992). The types and levels of support and training necessary for effective integration *and* intervention need to be clearly documented. Child care block grants and Parent Child Centers (Head Start) are increasing throughout the country and provide options for some families. However, early interventionists must learn more effective consultation and support strategies if optimal interactions and learning are to occur.

More Family Involvement and Support

Joyce Ford, in her reaction paper at the Hilton Perkins Conference on Deaf-Blindness in March, 1992, raised issues that parents with infants born prematurely, who are deaf-blind, have confirmed time and again . . . across many states: They become "dis-empowered" in the very early stages after their infant's birth. Individual families have shared the following statements that indicate how systems can "dis-empower" parents:

- "Not once did a social worker or any medical professional tell me that I had a choice. I was told that putting my child in an institution was the only solution. I knew that it wasn't mine."
- "If the social worker at the neonatal intensive care unit would have just given me the name of one other parent who had faced what I was facing, that would have been enough support for me at that time."
- "First you are told of all of the medical complications and you worry that your child won't live. Then they casually drop it on you that your child is blind. Then a week later, as an afterthought, they mention that he may not hear either, and they are not sure if he will have cerebral palsy."
- "They didn't provide any written information or any idea that there may be services available."
- "I was told that my child would never know me, could not feel pain, could not know love or love me. Now I know that I can communicate with her and she can communicate with me . . . and she does know love."
- "The Health Department tells me to take my child to a pediatrician who can deal with his problems. The social worker asks me if I have a regular pediatrician, and no pediatrician within 50 miles will accept Medicaid. I feel that I am caught within a vicious circle. My child doesn't sap my energy, the system does."

Although not all infants and young children who are deaf-blind will be born prematurely or will be in a neonatal intensive care unit (NICU) or intensive care unit (ICU), a new population of infants who are deaf-blind, or at risk for becoming deaf-blind is emerging (Stremel, 1989). A number of NICUs around the country are implementing practices such as (a) responsive interactions other than intrusive caregiving interactions, (b) environmental engineering to reduce intensive light and sounds, (c) parental involvement in feeding, changing, and interactions, and (d) parental support groups. However, many NICUs and hospitals do not do these things. Perhaps one of the areas most essential for family involvement is that of medical care.

Neonatal programs for infants who are deaf-blind and their families must improve nationwide. We, as educators, need to work more closely with the medical field to increase parental involvement in the earliest stages, to increase awareness and early identification, and to increase successful transitions into early intervention services. We don't need to "empower" families unless someone has initially "dis-empowered" them. Families need to know that they have choices and options and support at the earliest stages.

I would like to expand Deborah's discussion of family involvement and support with a brief discussion of two issues that families have reported are perhaps the most important for them. First, support from other parents and parent groups is essential. We, as professionals, can listen and be sensitive, but we cannot share our stories, our experiences, our knowledge if we have not walked in their shoes—only other families have that to share. We can assist families by connecting them to one another, even if just by phone and through videotapes. Second, respite programs are essential for many families. Whereas the intervener model provides families with respite services, additional funding sources must become available to expand various models and voucher systems to families.

Intervention Strategies and Procedures

I would agree that responsiveness, contingent stimulation, and caregiver-child interactions are important aspects of any early intervention program for infants/toddlers who are deaf-blind and their families (and all caregivers and interacters). It is even more important that receptive communication systems, recognition of expressive signals, partial participation, perceptual and tactile stimulation and discrimination, and motor movement patterns be taught within and across caregiving routines, interactions, and family activities by multiple persons who interact with the child. Families can determine which routines can initially be selected for intervention activities and which skills to target initially. The family's involvement in direct intervention activities should be directed by the family. This level of involvement may change across time, either increasing or decreasing.

Additional research needs to be conducted to determine when "typical" infants and young children perform skills that will be used for the remainder of their life. Milestones are reached when a child puts blocks in a container, but not when he or she throws paper in the trash or assists Mom in "washing dishes" or hands money to a store clerk. The emergence and importance of many of these functional skills will be based on cultural and family preferences. However, some of our initial research data indicate that some children will grasp a spoon prior to feeding, but not a rattle; a child will lift her arm four inches higher in range of motion activities when she helps to brush her hair, and that she will not extend back (display avoidance) when she wipes her own nose. Parents need to demand more functional skill training, as well as social interactional and play skills, in educational programs.

Future Directions

I imagine that one could describe the current state as one of "high levels of expectations, and low levels of funding and support." However, as long as parents, advocates, and service providers have high levels of expectations, we will continue to move forward. I would like to add some additional questions to Deborah's list.

1. Overall, are we identifying infants and children earlier and are services being provided? The 1991 Deaf-Blind Census (Baldwin, 1992) indicated that 1,076 children between the ages of birth and 36 months had been identified. This figure has increased since the passage of Part H. However, efforts in awareness and active referral could improve in order for infants to be identified earlier. That's the good news. The not-so-good news is that states reported that only 367 infants and toddlers were receiving early intervention services through Part H. Arcia, Keyes, Gallagher, and Herrick (1992) found that a substantial proportion of people who are eligible for services never enter the service system or do not use it to the full extent. People who are underserved may be in that condition due to the nonavailability of services or due to the underutilization of services. A number of the major determinants of underutilization of services include (a) ethnicity, (b) children of young mothers, (c) children whose mothers lacked formal education, (d) children of single parents, and (e) children from low-income families.

Attempts to increase services where limited services are available or where services are underutilized will differ widely. In these times of budget cutbacks and revenue shortfalls, all available funds must be utilized for service provision. Although not all families will be eligible for Medicaid and SSI, eligibility requirements have changed since April, 1990. Programs and service providers need to determine the categories of Medicaid eligibility, even though they are often numerous and confusing and vary across states. For example, states must provide hearing and vision services for children on Medicaid under EPSDT (Early and Periodic Screening, Diagnosis, and Treatment). Health coordinator/case manager functions can also be financed by Medicaid. Many families need assistance in negotiating the maze of eligibility requirements. However, many states are underutilizing Medicaid in financing services for infants and toddlers. Since many infants and young children who are deaf-blind do not have adequate hearing and vision assessments, the use of Medicaid to expand this service is important for the population.

Strategies for increasing the utilization of services that are available include increasing parent choice of services and being more responsive to cultural diversity. The use of parent facilitators and/or interveners from a specific culture needs to be increased to more fully include families of ethnic minorities, single parents, and low-income families.

2. Is assistive technology being fully utilized to meet the needs of the child? Service providers and coordinators of state and multi-state projects under Section 307.11 need to collaborate with the assistive technology center in their states (or determine if there is one) for the provision of early communication devices, adaptive switches, and adaptive motor equipment. Possibly the most under-used pieces of adaptive equipment for children who are deaf-blind are the hearing aid and hearing-assistive devices. Computer-assisted BEAR assessments and oto-acoustic emission assessments are available for earlier and more cost-effective, conclusive audiological assessments. However, many universities and diagnostic and evaluation centers do not have funds available to purchase this equipment. Families and professionals may have to approach community organizations and clubs to sponsor the purchase of state-of-the-art equipment for more intensive assessments.

3. Are early identification efforts being coordinated with all local and state agencies? Again, states are at different stages in the Child Find and Referral

components of Part H. The Part H lead agency is responsible, in cooperation with Part B, for early identification and referral. It is essential that coordinators of state and multi-state projects under Section 307.11 work in close cooperation with these agencies (a) to increase early identification for children who are at risk of becoming deaf-blind, (b) to increase timely referrals to early intervention programs, and (c) to work with these agencies in all transitions. The coordinators must also take a more active approach to work with tertiary hospitals and NICU staff for early identification and referral.

Quite possibly, the "ideal" service system is one that is put together with families and professionals in partnership with a strong local community commitment—a system that (a) realizes the value and potential of every child, regardless of the severity of the disability; (b) realizes the importance of the child in the family and of family decisions; and (c) realizes the importance of the family within its own community. Furthermore, if this individualized system doesn't work for the family at any given point in time, it should be changed. This is the intent of the Individualized Family Service Plan.

At least 1,076 infants and toddlers have been identified as deaf-blind, and possibly 500 or so are yet to be identified. Creative financing and pooling of resources are essential if comprehensive, collaborative, inter-agency, multidisciplinary early intervention services are to exist for them. Our job is to make the ideal service system a reality for every family that has an infant or young child who is deaf-blind, regardless of where the family lives. A truly comprehensive system will exist only when this "ideal" is a reality.

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POPULATION/DEMOGRAPHICS: PRESENTATION

Victor Baldwin

Abstract: Numbers and descriptions of those who are deaf-blind are presented. An emphasis is added that the real reason for gathering this information is to ensure that the population will receive the highest quality of services (rather than to satisfy the requirements of a grant proposal). The present census is a considerable improvement over past efforts and is beginning to reflect more accurately the actual incidence of dual sensory problems in the nation's population, birth to 21. We need to learn as much as possible about this population in order to establish a national repository of information that will include data for all ages and all levels of functioning. In addition, this data base should include a tracking system that will assist in reducing gaps in services and provide better ways to share information among programs. We need also to fund research projects that examine the uniqueness of the learning processes in persons who are deaf-blind. Results from this research should be used in personnel preparation programs and will lead to design of services that are more effective.

Assumptions

Before beginning a detailed discussion of the numbers and the descriptors of those who are deaf-blind, it is important to ask the question, "Why do we want to know this?" If the establishment of a national registry or annual census is developed solely for the reasons of satisfying the requirements of a grant or contract, then I suggest that we are terribly underestimating the usefulness of the information. The real reason to gather all possible data on each and every person who is deaf-blind is to ensure that these people are getting the highest quality services that the professions have developed.

When "highest quality intervention services" becomes the goal, the discussion about the importance of knowing everything possible about the population becomes extremely important. It is necessary to answer the following questions:

- Who are these people?
- What is the extent of their hearing and vision losses?
- Where do they live?
- What services are they receiving?
- What services do they need?

There are several other pieces of demographic data such as communication mode, functioning level, and mobility, that are also needed if the "highest quality intervention services" are going to be utilized.

There is another basic premise that needs to be agreed upon if the discussion of demographics is to have any importance. Does the label of "deaf-blind" carry with it the need for "extraordinary" intervention strategies? If not, the establishment of a directory or registry or some method of keeping track of these people is a total waste of time. If their dual disability does not necessitate the need for unique instruction beyond what would ordinarily be effective with persons who are singly blind or deaf, then there is little reason to create a separate category. If, on the other hand, the combination of a hearing *and* a vision loss can best be dealt with by utilizing unique teaching strategies that are different from those that are effective with the single disabling conditions, then it becomes

imperative to know who has a dual sensory impairment.

The Federal Definition

The 1990 federal definition suggests that the label of "deaf-blind" should only be considered when this "additional" condition for intervention exists.

> The term "Children with deaf-blindness," means children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities. (The Federal Register, Oct. 11, 1991, p. 51585)

The new federal definition not only ruled out programs that are designed solely for students who are blind or solely for students who are deaf, but also programs that are designed solely for students with severe disabilities. This later condition was added for the same reasons the first two were included, because of a concern that students who are deaf-blind were being placed in programs where the instruction might not focus on the unique conditions created by the dual sensory loss.

A Functional Definition

In recent years a "functional" definition has been proposed by this author that attempts to focus on the conditions for learning. Under this approach, the educational or intervention prescription will drive the diagnosis. The definition is dependent on the student's response to instruction and can be stated as follows:

> If the deficit in hearing *and* vision is sufficient to *require* special adaptations in instruction in *both* the auditory and visual modes to produce maximum learning, then the person qualifies to be identified as deaf-blind and should be included in the annual census.

This requires some experimentation to determine what approaches produce the most learning, but that is what good teaching is all about. Done correctly, this will affect the area of measuring student performance and evaluation of program effectiveness. Virtually every topic covered in this symposium is in some way dependent on knowing as much as possible about the population.

If the instruction or intervention required is unique, then identification of the population also takes on a special meaning for the professional preparation programs. If training programs are going to produce personnel that are qualified to work with persons who have a dual sensory loss, then they certainly need to know all they can about the population.

Using this more "liberal" functional definition runs some risk of overidentifying the population because it incorporates instructor judgment, but including "false positives" is far less harmful than not offering the services to those who could benefit. More will be discussed later about the "expected" size of the population and comparisons will be made with earlier predictions.

The fact that this population has unique disabling conditions and therefore special intervention needs, does not require or promote the development of programs that are separated or isolated. The "special" instruction or intervention can and should take place in naturally occurring environments with age-appropriate peers.

All of this is a backdrop to building a case as to why having a national census or registry can be a positive influence on the entire field and is *not* an attempt to segregate the population. To restate the original purpose, persons who are deaf-blind need special instruction and knowing who they are will assist in seeing that they are receiving appropriate services.

How Do We Achieve a National Registry?

At the present time there is no complete national registry or listing of persons who are deaf-blind. There are several "partial" attempts by various organizations to collect systematic information about certain subsets of the total population. The Helen Keller National Center (HKNC) has had a registry for a long time but it contains many errors and it has not been regularly updated. Much of the information is very old and ensuring that the data are accurate has not been a priority until recently. The Usher group has information on clients but it is restricted mainly to that particular syndrome. Other organizations have member lists but they typically involve some special subset of the total population based on issues such as vocational needs, geographic location, and interests. The one single effort that attempts to include *all* persons who are deaf-blind is conducted by the TRACES project and it has limitations because of a federal requirement to include only those people under 21 years of age. Also, it is limited as to the questions that can be asked.

This annual census that is conducted by the Teaching Research Assistance to Children Experiencing Sensory Impairments project (TRACES) on behalf of the U.S. Office of Education, will be the basis for most of the discussion throughout the rest of this document. Some general background information will help the reader better understand the rationale and the scope of the effort.

Background

As a result of the rubella outbreak in the early 1960s there was a dramatic increase in the number of newborns experiencing problems in *both* hearing and vision. This unfortunate situation raised the national awareness of the unique needs of this population sufficiently to create a separate funding base in 1969 for this disabling category (now Section 307.11) of children considered to be "deaf-blind." This authority focused on children from birth to age 21.

In order to dispense these new funds equitably across the country, a network of single-state and regional centers was established. In the early stages of this federal funding, eight single-state and eight multi-state centers were supported. These centers received money directly from the Bureau of Education for the Handicapped (now called the Office of Special Education Programs) and distributed the funds based on proposals they received from their specific service regions (individual states or multi-state regions). The funds could be spent on direct services, and the decision as to how the money was allocated depended upon which organization wrote the most compelling proposal to provide services for the children they had identified as deaf-blind. Since some states or regions had conducted better child identification and developed strong service delivery systems, it was fairly common to see a distribution of funds that was not highly correlated to the overall population of a state. Stated otherwise, states or regions that had good programs were more likely to submit strong proposals and receive more funds.

Several attempts at establishing a national registry of children and youth who are deaf-blind date back to the beginning of the federal program in the 1960s. A definition of the condition was developed at the government level in the late sixties to guide

the classification of these students and the subsequent census, but it wasn't until 1986 that an annual count was *mandated* in the regulations. Up until that time, any effort to collect information centrally about people who are deaf-blind was done on a "good faith" basis, since collection of population data was not "required" at the federal level. This resulted in a general under-counting nationwide of the population.

This situation has been altered, however, with the child count data being tied to the special education census required of each state Department of Education. Early in December of each year, every state Director of Special Education is required by federal law to turn in a report that accounts for all disabled children a state is serving under either P.L. 94-142 or P.L. 89-313 programs. These documents require that each child be identified under a specific disabling condition. One of the available categories is deaf-blindness. At that same time, a report is submitted by the coordinator of the state and multi-state projects under Section 307.11 indicating how many children who are deaf-blind are served in educational programs. Early comparison of the two reports by federal officials generated many unanswered questions about the population and became a source of embarrassment when the data from the mandated P.L. 94-142 and P.L. 89-313 counts were compared with the "voluntary" count of students who are deaf-blind. There was a large discrepancy among these data sets that required an explanation.

For example, in 1985 the state departments of education reported the numbers of "deaf-blind" children they were serving, in both P.L. 94-142 and P.L. 89-313 programs, was approximately 1200. In that same year, the coordinators reported approximately 2400 children and youth being served. This prompted the U.S. Office of Education to request an examination of this issue and determine the reason for this large discrepancy. Teaching Research (at Western Oregon State College) was already conducting the National Technical Assistance Project for Deaf-blind Children and Youth and therefore responded to the request.

Inspection of the available databases and meetings with several state directors of special education revealed that most of the children the coordinators were including in their censuses were also the ones being reported in the state P.L. 94-142 and P.L. 89-313 counts as multi-disabled. The state administrators did not argue that these children were *not* deaf-blind or dual sensory impaired, but they—or the school district—had chosen to count them under the category of multi-disabled. As a matter of fact, these directors stated that most of their more severely impaired students were experiencing a dual sensory impairment. Quite simply, in many cases these children were in classrooms for multi-disabled students and, therefore, were categorized in similar manner. Also, some administrators voiced the thought that if they used the label of deaf-blind their programs could be found in noncompliance since they had no specific programs or teachers who had training with children who are deaf-blind.

This issue raises some serious ethical questions. If a student is experiencing a vision *and* hearing impairment, then the instruction they receive should take these into account, *regardless* of whether or not they are labeled "deaf-blind" on the state census report. For these reasons, we have proposed the previously mentioned "functional" definition of the "deaf-blind" category that allows the educational prescription for the student's intervention to drive the selection of a disabling category.

The functional definition that we endorse may appear at first glance to be more lenient than the current federal position, but close

examination of the instructions that accompany the federal forms indicates that rigorous audiological and ophthalmological measurement is not required. Although the instructions suggest a person needs, at a minimum, to have a visual acuity of 20/70 in the better eye with correction *and* an auditory deficit of 30 db in the better ear, to be included on the National Census, there are ratings available in the categories of "tested-results nonconclusive" and "not tested." These later categories make it possible to include an individual who has not had formal visual and audiometric evaluations. In these cases, a professional judgment about the intervention need would seem to be appropriate. This could lead to overidentification, but such errors are less of a problem than underidentification, as the prescriptive nature of the educational intervention would ensure that the student was receiving appropriate instruction.

We argue that anyone who meets the functional definition should be reported as deaf-blind by the coordinator regardless of the disabling category that the state has assigned on the annual 94-142 and 89-313 count. It is our position that because coordinators have been designated (by job definition) to be responsible to see that all students who meet the definition get an "appropriate" education, they should include these students in their counts. In addition, if the coordinators do include a student in their counts, they have, in effect, stated publicly that they will monitor the instruction to ensure inclusion of adaptations in both the visual and auditory modes.

Although the federal government has a published definition, it does not take precedence over a state's definition. There has not been a systematic effort to collect and analyze the various state definitions although such a study is underway at the present time by the TRACES project. The past five years experience of working with all of the coordinators in developing a national census, would suggest a combination of the functional definition and the federal definition is most commonly used, and in actual practice there is no single agreed-upon definition for this category.

The National Census for Deaf-Blind Children and Youth

Nearly all of the descriptions and assumptions in this section are based on the database that makes up the National Census for Deaf-Blind Children and Youth, ages 0 to 21. This census is maintained by Teaching Research (TR) for the federal Office of Special Education Programs. The census is produced annually as a result of the federal mandate that requires each coordinator to report the numbers (census) of children who are deaf-blind in their jurisdiction. These data are initially collected each December at the same time every state department of education conducts the annual P.L. 94-142 and P.L. 89-313 counts. These state reports are not finalized until March and are generally not ready for printing by the federal government until summer or fall. In essence, this means the most current population data are always one year old before they are available to the public. The data presented here are based on the official count from all states and territories that occurred in December of 1991.

The census became an official requirement to receive funding to serve children who are deaf-blind and TR was given the responsibility to collect and analyze the data in 1986. Preliminary review of the data available to that time indicated there were significant problems with the existing information on students who are deaf-blind. It was obvious that there was little relationship between a population of a state and the number of children who are deaf-

blind being reported. There were some states with average size populations reporting more students who are deaf-blind than very large states, and some large states reporting fewer than the small states. It seemed logical to assume that the national incidence of deaf-blindness should be fairly equally distributed across all states as some reasonably consistent proportion of the population of a state. For example, a consistent proportion of students identified as disabled (10 to 12%) in relation to all students exists in virtually every state and territory. It follows that a predictable incidence of deaf-blindness for the entire country should be able to be determined based on incidence data from selected states.

In order to make accurate estimates, we decided to examine a few states that had a good probability of correctly reporting the number of children who were deaf-blind. A sample was chosen of six states that had a small total state population and a Title 6-C coordinator who had held the job for three or more years. The primary assumption was that it was unlikely there would be many school-age children who were deaf-blind that the coordinator would not know about. Thus, the incidence rates in these states were more apt to be accurate than rates derived from states in which the coordinator was new, or that were large and encompassed several million people. The six states chosen were Colorado, Kansas, Montana, Oregon, Utah, and Washington. The ratio of students who were deaf-blind to the total of children with disabilities reported in these states was remarkably consistent.

Based on this sample, the expected mean incidence of deaf-blindness is .00207 (standard deviation of .0005), of the total number of students a state serves in its special education programs. (This ratio of approximately 2 students who are deaf-blind per 1000 disabled students has remained very consistent over the last four years in these six states). We then used this mean incidence ratio and standard deviation to predict the expected number and age of children who are deaf-blind ages 0 - 21. Specifically for each state, we multiplied the mean incidence (.00207) by the total number of special education students served. The range of expected numbers of students who are deaf-blind (at least with a 68% range of certainty) was based on this mean, plus or minus one standard deviation (.0005). For example, if a state reported that it served 30 thousand special education students, the mean number of students who are deaf-blind to be expected would be 62. The range of students to be expected in the state would be from 47 to 77. Attachment A presents a state-by-state comparison of the total number of students in special education, the actual count reported by the coordinators, and the "expected" numbers and range of children who are deaf-blind. The actual 1991 total count of children and youth who are deaf-blind is 7,839. Based on the "expectation" formula described above, there should be a mean of 9,965 students reported, with a range from 7,657 to 12,274.

There are 61 states and territories eligible to report in the registry. Examining the results by comparing the coordinator's report with the plus or minus one standard deviation expected range, indicates that 29 states are within the expected range, 10 are over the expectations or "over-counting," and 18 are apparently "under-counting." Despite these discrepancies, we should stress that these data represent a vast improvement since the first mandatory reporting period of 1986 when the total reported number of children and youth who are deaf-blind was 2400. Further, there may be valid reasons behind some of these differences; thus, a close examination of each state or territory's count is warranted.

There are other types of demographic data available from the national census. On the federal forms there are spaces and instructions for providing information about the major cause of deaf-blindness, gender, the category of disabling condition the state department has assigned to the student, the federal funding source, any additional disabling condition(s), the degree of vision loss, and the degree of hearing loss, the setting for the educational services and the living arrangements. For each of these areas of information there are instructions and specific codes that are to be used. The person who fills out the report can use only the codes that are provided, even though they may not be comprehensive or adequately describe the student's actual condition. Accordingly, caution must be exercised when reviewing these data. The following is a summary of the various categories of information that are available from the most recent census (December, 1991). It should be noted that New York, Tennessee, and the Virgin Islands did not turn in a new census for 1991 and therefore some of the "new" categories of information have missing data.

Etiology or major cause of deaf-blindness. The categories for reporting etiology changed in 1991. The information on the old form was thought to be too narrow and limiting and several new items were added. A listing of the categories and the frequency of their occurrence can be seen in Attachment B. Obviously a problem still exists because of the large number of responses under the category of "other (not specified)." In essence, people are leaving this section blank because they do not know the etiology. The single most frequent *specific* cause that was reported was prematurity. The lack of information on the topic of etiology is one of great concern and raises questions about the availability of the background information on these students.

State Department of Education label. The next summary can be misleading without an understanding of the federal instructions. The respondent is to record the disabling condition that his or her particular State Department of Education has assigned to each student. We know if the child is on this census that the person filling it out thinks that the person is deaf-blind, but that is not what is asked for here. This section is used to document specifically how the state has recorded the child on either the P.L. 94-142 or P.L. 89-313 count. By examining the following categories and numbers it is possible to see how the state or school districts labeled these students that the coordinator has identified as deaf-blind.

Mental retardation	1118
Speech impaired	194
Emotionally disturbed	44
Orthopedically impaired	110
Other health impaired	692
Learning disabled	81
Multi-disabled	2096
Hard of hearing	189
Deaf	275
Visual disabled	411
Deaf-blind	1154
Traumatic brain injury	7
Autistic	241
No data	1227

It is important to remember that the categories used in the above description are the ones the states use from their P.L. 94-142 and P.L. 89-313 data bases. For reasons stated earlier, it appears that most students with dual sensory impairments are classified by states as multi-disabled and are probably in those programs. This, by no means, suggests these children do not need special instruction that takes into account their dual sensory loss, but it does raise questions as to whether or not such instruction actually occurs.

Additional disabling conditions. The coordinators of programs for those who are deaf-blind also have the opportunity to

provide information about any other primary disabling conditions that are present in addition to deaf-blindness. Again, they can only code the categories available to them on the national census forms. Following is a listing of the additional primary disabling conditions and the corresponding reported numbers.

Mental retardation	4410
Speech impaired	3287
Emotionally disturbed	883
Orthopedic impaired	3158
Other health impaired	1983
Learning disabled	354
Autism	784
Traumatic brain injury	174
Other	587

Most students who are deaf-blind are identified as also having mental retardation in addition to their dual sensory impairment. As can be seen from the above data, additional disabling conditions occur quite frequently.

Vision loss. Under another section of the form the respondent has the opportunity to describe the degree of vision loss. The instructions, once again, spell out the criteria and only the available categories can be used. The degree, criteria and the reported numbers are as follows:

Partial sighted—(20\70-20\200)	1240
Legally blind—(less than 20\200 or 20 degree field)	2186
Light perception only—	1018
Totally blind—	1137
Unknown—(not found in the records)	278
Not tested	439
Tested - results nonconclusive	1541

The "unknown" category usually means the students have not been formally tested or the coordinator is not aware of any assessment. The largest group falls into the category of legally blind.

Hearing loss. Just as in the vision area, there are given categories and criteria. Once again, the options are provided to indicate that the student has not been tested or tested with nonconclusive results or it is unknown if testing has occurred. Below is a listing of the categories, criteria and numbers for this section of the report.

Mild—(30 - 50 decibel loss)	973
Moderate—(56 - 80 decibel loss)	1525
Severe—(81+ decibel loss)	1900
Unknown—(not found in the records)	330
Not tested	427
Tested, nonconclusive results	1363

The most frequent category checked is severely hearing impaired. When this is compared to the vision area it would appear that the population, as a whole, is considered more hearing impaired than vision impaired. This finding is important for considering the types of services that will be needed for this group of individuals. Stated otherwise, students who are deaf-blind in this country would appear to be more "deaf" than they are "blind." Accordingly, teachers should be skilled in an appropriate communication approach to interact with and teach effectively the majority of the population.

Living arrangement. This is another new category for 1991 and therefore some of the data are missing because of the three states that did not submit new data. The settings and the frequencies are as follows:

Birth/adoptive parents	5061
State residential facility	681
Private residential facility	491
Foster parents	359
Extended family	111
Other	106
Group home (6 or more)	79
Group home (less than 6)	67
Apartment with non family	6
No data	878

The vast majority are living at home with birth or adoptive parents. Unfortunately,

there is a large hole in the data, but because of the predominance of the findings in the other states, this trend would probably not change.

Educational setting. This also is a new category of information. The federal instructions spell out the definition or requirements for each of the educational categories so that the respondent can make clear distinctions as to how to identify a program. The following are the settings and frequencies of the educational programs.

Separate class public school	2831
Separate public school	1354
Public residential facility	646
Home/hospital setting	618
Private residential facility	407
Other	389
Separate private school	294
Regular class public school	245
Resource room public school	224

Clearly the most prominent educational placement is in the public school. This is the one data set that can be somewhat compared to an earlier report in 1980 in which Robert Dantona summarized the federal deaf-blind program. At that time he stated that of the estimated 6000 students who were deaf-blind approximately 53% were getting education in a residential school for children who are deaf or blind or in a state institution for the retarded, and about 43% were in day school programs. He summarized the results and made a plea for deinstitutionalization and more community-based programs. Some significant strides have been made in that direction. This year the data suggest that only 20% of the students are served educationally in residential schools and state institutions while 66% are served by the public schools.

Gender. Being able to report on the gender of the students is new in the latest census. This is one category that most states could fill out correctly; however, one state lists 100 students as having an unknown gender. This has been pointed out to the coordinator and will be corrected in the next census. The overall results show 55% male and 45% female. This is in line with other studies of the distribution of disabling conditions across gender.

Age distribution. For the first time there does not seem to be a peak or blip in the distribution of ages across the birth-to-21 age span. The actual age distributions by individual states can be seen in Attachment C. In the past there has been a bulge in the middle teenage years and a sharp drop at both ends. Earlier reports showed a drastic jump in the numbers at about age 4 or 5 or when they got close to school age. This year the data show a near level effect at these early ages. It has been hoped for some time that, with the advent of Part H programs, more of the children with dual sensory disabilities would be identified earlier and referred to appropriate programs. On the other end of the scale there is still a drop in the numbers after 18 but it is less dramatic. These age breakdowns show an average of about 375 students at any one age group. As these students age out of the educational program they are often picked up by other agencies and services and are no longer counted by the state or multi-state coordinator. At the same time, we know that the numbers of persons who are deaf-blind increase with age because of late onset of medical conditions, accidents, and other side effects of getting older. Whether or not these "graduates" of the programs and others who come into the picture later, continue to get services or what happens to them is not systematically monitored across the country. The birth-to-21 census that is required by the Office of Special Education Programs is the only *mandated* count that is coordinated in one location for all of the states.

Summary

There is no national central repository of demographic information about persons who are deaf-blind that covers all of the age ranges. The information that is available is fragmented along specific interest lines. Whether or not there ought to be such an information base depends on the strength of the arguments that the population has unique needs and the information to be collected can help ensure that the people will receive the highest quality of services. If the requirement for "special intervention" strategies is to be effective in working with this population, then there are major implications for personnel training programs.

The only "mandated" approach to gathering systematic information about persons who are deaf-blind is the annual census on students between birth and age 21. Although this information is very helpful, it is still limited by the nature of the age range and the relatively few questions that are asked. Even with the limits of the census, it has been possible to see considerable change in the field. More children are being identified at an earlier age. The numbers of persons at each age range appear to be equalizing and there is no large bulge at the moment. There now appears to be a definite correlation between the number of people who live in a state and the number of students who are deaf-blind. This more "normal" distribution of the population would suggest that the identification procedures across the states are becoming more similar.

The general expectation that there will be "approximately" two students who are deaf-blind for each thousand special education students (birth to 21) puts today's estimate a couple of thousand higher than in 1980, but there has also been a population increase. By using a generous standard deviation range, most states have identified enough students to feel they are including most of the people who need the special services. There are still some states that appear to be underidentifying students but most of them are working with a difficult bureaucracy and it is difficult to obtain the necessary information. There are some programs that feel that they are using such rigorous evaluation criteria that they will probably always remain low in their count. Regardless of the individual reasons for fluctuations in the count, the estimate of two students who are deaf-blind per thousand special education students is probably closer to what is really out there rather than, for example, one in a thousand which would put the count at about only five thousand, or three in a thousand, which would put the average up around 15 thousand.

State departments of education prefer to label students who are deaf-blind as multiply disabled. Fighting the battle to change this would probably take more time than it is worth. The critical issue has to do with whether or not the person is both vision and hearing impaired and if they are getting instruction that takes both losses into account. This can be done without getting the state to change a label.

A vast majority of the children are living with their natural or adoptive parents. A significant educational change has occurred in the last 10 to 12 years in that about 66% of these students are now enrolled in the public schools.

Recommendations

To ensure that people who are deaf-blind receive the highest quality services, the following steps should be taken:

1. Establish a national repository that will collect information about people who are deaf-blind. The data should come from all

sources that now gather information on any aspects of deaf-blindness. All age ranges and levels of functioning should be included. This would provide the basis for determining what data sets are not available and what additional information is needed. This will require the close cooperation between the various arms of state and federal government to not only share their present information but authorize the collection of the additional needed information.

2. At a minimum, call all of the above "information holders" together to discuss the parameters of the existing data, identify needs, and suggest next steps.

3. Couch the concept of a national data base within the notion of a tracking system that would assist in reducing the gaps in service and provide better ways to share information among programs.

4. Fund research projects that will examine the uniqueness of the learning issues for persons who are deaf-blind. These findings should have major implications on the types of information needed to design effective programs. They should also greatly influence personnel preparation programs.

References

Federal Register (1991, October 11). Vol. 56, No. 198. Washington, DC: U.S. Government Printing Office.

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Attachment A
1992 DEAF/BLIND COUNT - ACTUAL COUNT vs EXPECTED RANGE

State	[4] All Spec Ed (Birth to 21)	[5] 1992 D/B Report	+1SD	EXPECTED	-1SD
Alabama	94945	158	242	197 [2]	151
Alaska	14745	21	38	31 [1]	23
Arizona	57235	81	146	119 [1]	91
Arkansas	47835	83	122	99 [2]	76
California	469282	1206	1197	972 [2]	747
Colorado	57198	143	146	118 [2]	91
Connecticut	64562	43	165	134 [1]	103
Delaware	14294	38	36	30 [3]	23
Dist of Columbia	6290	16	16	13 [2]	10
Florida	236674	246	604	490 [1]	377
Georgia	101997	189	260	211 [2]	162
Hawaii	13169	49	34	27 [3]	21
Idaho	22017	58	56	46 [3]	35
Illinois	248045	300	633	514 [1]	395
Indiana	114643	199	293	237 [2]	182
Iowa	60695	48	155	126 [1]	97
Kansas	45212	98	115	94 [2]	72
Kentucky	79444	110	203	165 [1]	126
Louisiana	73663	107	188	153 [1]	117
Maine	27987	22	71	58 [1]	45
Maryland	91940	138	235	190 [1]	146
Massachusetts	154616	145	395	320 [1]	246
Michigan	166846	204	426	346 [1]	266
Minnesota	80896	195	206	168 [2]	129
Mississippi	61031	151	156	126 [2]	97
Missouri	101955	168	260	211 [2]	162
Montana	17204	42	44	36 [2]	27
Nebraska	32761	88	84	68 [3]	52
Nevada	18440	45	47	38 [2]	29
New Hampshire	19658	50	50	41 [2]	31
New Jersey	181319	369	463	376 [2]	289
New Mexico	36037	83	92	75 [2]	57
New York (data from 1990)	307458	598	784	637 [2]	489
North Carolina	123126	341	314	255 [3]	196
North Dakota	12504	38	32	26 [3]	20
Ohio	205440	315	524	426 [1]	327
Oklahoma	65653	137	168	136 [2]	104
Oregon	55149	88	141	114 [2]	88
Pennsylvania	219428	185	560	455 [1]	349
Puerto Rico	35129	32	90	73 [1]	56
Rhode Island	21076	48	54	44 [2]	34
South Carolina	77765	67	198	161 [1]	124
South Dakota	14987	50	38	31 [3]	24
Tennessee (data from 1990)	104898	28	268	217 [1]	167
Texas	350636	238	895	726 [1]	558
Utah	47747	113	122	99 [2]	76
Vermont	12263	33	31	25 [3]	20
Virgin Isles (data from 1990)	1333	12	3	3 [3]	2
Virginia	113971	207	291	236 [2]	181
Washington	85395	116	218	177 [1]	136
West Virginia	43135	75	110	89 [2]	69
Wisconsin	86930	139	222	180 [2]	138
Wyoming	11202	23	29	23 [2]	18
Pacific Basin (Samoa, Guam, N. Mariannas, Palau)	2646	63	7	5 [3]	4
TOTALS	4810506	7839	12274	9965	7657

[1] Under counting by more than one standard deviation.
[2] Count within acceptable estimate range
[3] Over counting by more than one standard deviation.

[4] The "All Spec Ed" counts are from the Dec 1990 State Reports
[5] The D/B Report is from the December 1991 622-C Count

ATTACHMENT B

Major Cause	Frequency
Other (not specified)	2864
Other (Syndrome)	555
Prematurity	486
Rubella	454
Other (Multiple Congenital)	421
Other (Congenital Prenatal)	334
Microcephaly	290
Meningitis	269
Other (Post Natal)	231
Asphyxia	191
Hydrocephaly	187
Head Injury/Trauma	176
Usher	170
CHARGE association	119
Encephalitis	95
Down Syndrome	68
Trisomy 13	36
Fetal alcohol syndrome	33
Toxoplasmosis	33
Maternal drug abuse	32
Stroke	27
Herpes	22
Syphilis	4
AIDS	2

*No data on 740 cases

9-25-92

ATTACHMENT C

	CHILD COUNT REPORTED UNDER...			RECEIVING PART-H SERVICE	CURRENT AGE OF CHILD								TOTAL COUNT
	Unknown	PART-B	CHAPT-1	YES	0-3	4-6	7-9	10-12	13-15	16-18	19-21	Unknown	
ALABAMA	63	95			53	26	22	7	12	21	17		158
ALASKA	4	16	1	3	6	4	3	3	2		3		21
ARIZONA	21	30	30		13	13	13	15	9	11	7		81
ARKANSAS	8	33	42	1	5	15	19	20	8	11	5		83
CALIFORNIA	35	1086	85	35	92	161	199	225	178	191	160		1206
COLORADO	38	105		34	51	24	11	10	15	13	17	2	143
CONNECTICUT	4	8	31	3	3	10	6	7	8	4	5		43
DELAWARE			38	1	4	4	9	11	4	4	2		38
DISTRICT OF COLUMBIA	1		15			3	4	4	2	2	1		16
FLORIDA	7	184	55		30	48	45	30	36	31	26		246
GEORGIA	4	70	115		48	43	29	18	13	23	15		189
HAWAII		46	3		4	8	9	8	11	8	1		49
IDAHO	11	39	8	5	12	10	12	7	12	5			58
ILLINOIS	64	26	210	49	77	57	29	50	31	27	29		300
INDIANA	16	52	131	13	26	33	24	38	27	28	23		199
IOWA		30	18		1	6	8	12	5	10	6		48
KANSAS	8	59	31		15	15	27	12	12	12	5		98
KENTUCKY	7	62	41	4	6	16	22	28	12	19	6	1	110
LOUISIANA	10	35	62	3	10	7	19	20	15	17	19		107
MAINE	5	15	2	2	2	6	5	5	1	1	2		22
MARYLAND	7	103	28	14	28	22	29	22	14	13	10		138
MASSACHUSETTS	145			7	25	34	19	19	17	13	10		145
MICHIGAN	2	42	160	5	28	42	27	35	28	31	13		204
MINNESOTA	11	161	23	3	4	17	28	54	40	30	15	7	195
MISSISSIPPI	10	101	40	1	12	26	33	31	21	18	10		151
MISSOURI	8	108	52	8	14	27	29	29	30	20	19		168
MONTANA	21	15	6	12	12	5	8	5	6	2	4		42
NEBRASKA		83	5	12	8	14	13	13	15	16	9		88
NEVADA	10	32	3	7	14	10	7	7	2	4	1		45
NEW HAMPSHIRE	7	25	18	5	13	14	7	8	3	4	1		50
NEW JERSEY	1	35	333		104	112	23	40	28	32	30		369
NEW MEXICO	10	55	18	8	10	14	14	15	9	11	10		83
NEW YORK	15	99	484		5	45	117	124	130	83	89	5	598
NORTH CAROLINA	16	208	117	10	33	47	63	49	53	48	48		341
NORTH DAKOTA		7	31	10	11	4	6	8	3	6			38
OHIO	3	264	48	9	35	53	44	58	48	48	29		315
OKLAHOMA	7	119	11	5	15	18	26	29	26	11	11	1	137
OREGON	7	1	80	16	15	16	17	14	8	11	6	1	88
PENNSYLVANIA	14	90	81	12	51	31	26	23	20	17	17		185
PUERTO RICO		32					3	7	9	7	6		32
RHODE ISLAND	7	30	11	6	7	14	10	7	3	3	4		48
SOUTH CAROLINA	12	11	44	1	14	8	9	8	15	7	6		67
SOUTH DAKOTA		31	19	2	3	3	12	10	10	9	3		50
TENNESSEE	28					2	5	4	8	6	3		28
TEXAS	19	98	121	16	36	39	38	30	37	29	21		238
UTAH	23	62	28	11	26	20	15	23	11	10	8		113
VERMONT	3	12	18		5	5	9	6	2	2	4		33
VIRGIN ISLANDS	12			18		1	4	1	1	1	1	3	12
VIRGINIA	5	187	15		27	49	40	37	23	15	10	6	207
WASHINGTON	58	22	36	1	25	14	16	19	12	14	16		116
WEST VIRGINIA	8	34	33	8	16	11	9	12	11	6	10		75
WISCONSIN		120	19	2	11	32	18	32	16	21	9		139
WYOMING	16	7		5	6	2	2	5	3	2	3		23
PACIFIC BASIN	49	3	11		5	12	20	14	5	3		4	63
TOTAL COUNT	840	4188	2811	367	1076	1272	1261	1336	1080	991	793	30	7839

POPULATION/DEMOGRAPHICS: REACTION PAPER

Marianne Riggio

Abstract: Accurately defining the population of children and youth who are deaf-blind is essential if we are to provide high quality educational services. We must therefore create a more accountable system for identification which will include screening and formal diagnostic evaluation in conjunction with functional assessment. A task force made up of professionals, consumers, and family members could establish such a system. The criteria by which Section 307.11 proposals are evaluated should specify how well-informed the project is about the children it proposes to serve; their process for identification; and how aligned the direct services and technical assistance are to the needs of individual children and their families. Categories of "unknown" and "not tested" should be eliminated from census forms and child count should not be a separate factor within the funding equation. With clearer knowledge about the individuals to be served under Section 307.11, high quality centers of expertise can be developed to provide information, training, advocacy, and support.

I am honored to be selected to be a part of this very important symposium designed to rechart the course of services to people who are deaf-blind in our country.

When we speak about issues of population, and who is deaf-blind, we are talking about the children and young adults who are at the heart of everything we do. Knowing as much as possible about these people should be our primary responsibility. If we do not know them, it is impossible to plan and provide services to meet their unique needs.

Goals of Data Collection

Vic, in his presentation, has touched upon some very important points. In his opening statements, he outlined information which must be collected to help us move toward the goal of providing the "highest quality intervention services," and he has acknowledged that, with the label of "deaf-blindness," comes the need for "extraordinary intervention." As I speak with you this morning about issues of child count and program eligibility, and as we re-evaluate efforts of state and multi-state programs under Section 307.11 to meet the unique needs of infants, toddlers, children, and youth who are deaf-blind, we must keep that goal of highest quality services in mind. We want to return integrity to the education of children who are deaf-blind as we endeavor to chart future directions.

Uniqueness of the Population

Over the past decade, we have been challenged to prove the uniqueness of the educational needs of children with combined vision and hearing impairments as compared to other children with multiple disabilities. In the most recent reauthorization, the Individuals with Disabilities Education Act (IDEA) clearly acknowledges that deaf-blindness is a unique disability requiring a categorical program. This affirmation has given us new hope and new energy to work together to improve the quality of services to individuals with this disability.

In preparing my response, I have thought a great deal about my own experiences during

which I have worn many hats: from an untrained student volunteer to a teacher of children who are deaf-blind; to consultant to programs serving children who are deaf-blind; to coordinator and project director of Section 307.11 services. I have reflected upon my training as a teacher of children who are deaf-blind, and how it differed from my training as a teacher of children in regular education and those with special needs. Most important though, I thought about two issues:

- How unique were the children whom I have known and taught?
- What information did I have about how they learn that other teachers who were not trained needed to have in order to meet the educational challenges presented by the children who are deaf-blind in their classrooms?

I think as we speak about definition, it is important to reflect on the passage of the original legislation authorizing development of centers to serve children who are deaf-blind. As you all are aware, these services were established in response to the unique population of children born during the rubella epidemic in the early 60s. This group of children had in common documented vision impairments caused mostly by glaucoma and cataracts and sensory-neural hearing losses of varying degrees. These combined losses necessitated unique and specialized teaching methods to allow for the development of communication, mobility, and interpretation of a wide array of information in the environment.

When we talk about vision and hearing impairment it is common to refer to these as the distance senses. The presence of these combined sensory losses necessitates that we approach teaching in a much more intimate manner; a manner which is dramatically different from what are considered standard instructional practices in regular and special education. Children who are deaf-blind are much more heavily reliant on other people to assist them in interpreting their environment. This involves the building of strong, trusting, personal relationships between the instructor and student, and all significant people in the lives of that person. In order to enable people who are deaf-blind to express themselves, we must use modes of communication which are not typically used by sighted and hearing individuals, but which are more natural for a person without hearing and vision.

I have calculated that we currently have available $1148.10 per child for state and multi-state centers to provide a vital service. With this limited pool of funding, it is essential that we are careful to develop a uniform standard for deciding which children should be the recipients of these services. If we propose that children should be counted who require adaptations in instruction in auditory and visual modes to produce maximum learning, then we are throwing ourselves open to including every child with visual and auditory learning disabilities, and many children with a host of other disabilities who require adaptations in vision and hearing. Many children require these adaptations who are not truly hearing or visually impaired. The issues of deafness and the issues of visual impairment are quite different. Indeed many of the children we serve have, in addition to a hearing/vision impairment, additional learning disabilities; however, it is by virtue of their sensory losses that they are called deaf-blind.

Even with a definition that requires documented hearing and vision loss, we are still going to be serving a wide array of children with a wide array of disabilities. We will serve children with disabilities such as those associated with Usher Syndrome, who may choose to go on to college and professional lives; children such as those with CHARGE Association who may have complex health care needs, yet possess the

potential, given appropriate educational services, to achieve at a very high cognitive level; other children who will have limited potential for independence by traditional standards; and others, such as those with Trisomy 13 for whom the prospect of living long enough to reach school age is not promising, but for whom we hope as teachers to assist their families in developing a mutually enriching relationship with their child as long as they are together.

Importance of Diagnosis and Evaluation

As providers of services to children who are deaf-blind, we must advocate for screening and formal diagnostic evaluation *in conjunction with* functional assessment. This is the only way we will be able to develop appropriate systems of communication, determine modes of instruction, and decide to what extent the capacities of the child are affected by his or her vision or hearing impairment, as opposed to being a function of additional cognitive or perceptual disorders.

In our educational system today, we have, as a profession, acknowledged the rights of all people with disabilities to equal access to education within their home communities. I think, however, we are not truly holding to these ideals as we provide services if we are saying that we should not have to bother with formal testing of children's vision and hearing. Even though we espouse quality and equality, we are witnessing very much of a double standard, and much diminished quality in services. The issue of not requiring vision and hearing evaluations on children whom we are counting as deaf-blind is an example of this.

We all remember back in our elementary school days that at the beginning of every school year we were ushered into the nurse's office where we were told to raise our hands at the sound of the tone, or read the "tumbling E" chart. Any child who was unsuccessful had a note sent home to parents requiring that they seek further ophthalmological or audiological assessment. In children with developmental disabilities and limited access to information, these assessments are all the more important. We need to know how much visual information a child is receiving and how much hearing they have that is useful in order to maximize their opportunities for learning.

Under the mandate of P.L. 94-142, children are entitled to a free and appropriate public education. As part of this education, they are also entitled to appropriate diagnostic testing in order to develop their educational plans. It should, therefore be a part of the role provided by the state and multi-state projects under Section 307.11 to ensure that children who are suspected of vision and auditory impairment have appropriate testing.

I differ with those who see a need for a sole functional definition where the "prescription drives the diagnosis." The intervention chosen will be considerably different depending on the cause and nature of the disability. A child with a profound hearing loss caused by damage to the middle or inner ear will require very different methods of instruction than those for one who is centrally (cortically) deaf.

To illustrate this point, I'd like tell you about Marco. He was born without eyes or a nose and had a cleft palate. Had we taken the posture that Marco did not require audiological testing, a teacher's developmental evaluation would have revealed that he could respond to many sounds, but could not localize to them. Auditory localization is a skill that is typically acquired when a child is very young. This teacher could have therefore determined that, because he was six years old, Marco was severely delayed. Fortunately, Marco had

audiological evaluation which revealed a profound hearing loss in one ear and only a mild loss in the other, making a dramatic difference in the interventions chosen.

In this case, as a deaf-blind specialist, it was important for me to help interpret the information in the audiogram and its implications, and help modify teaching approaches to enable Marco to understand his environment. This included adapting the way his mobility training would need to be addressed, which would differ from standard practices used with blind children, and to develop a functional communication system that he could use at home and in school.

I think too of Michael who had a traumatic head injury, and whose neurological records indicated specifically which portions of his brain had been most severely damaged from secondary hemorrhages. It was important for Michael's teacher to have a professional develop a hypothesis about the manner in which this damage would affect his vision. Then, the professional could provide assistance in the assessment of functional vision and make recommendations for instructional modifications.

Refining our System of Data Collection and Project Analysis

The Teaching Research Division should be commended for the work they have done in collecting data about the children served through state and multi-state projects under Section 307.11. Such a census is important to ensure that children who are deaf-blind are receiving the highest quality services that are possible. I think, however, there is a great deal of work which must be done before we can say that this information is truly representative of the population, or that Section 307.11 projects around the country are using this information to guide their work.

Under the current system, there are no checks and balances. When Vic spoke about the state that cannot identify the gender of its students, this tells me that our states are not focusing on what should be the pulse of the field—the children. I am also concerned about the numbers of children who have not had their hearing and vision tested or of whom the Section 307.11 coordinator has no knowledge. A state could plug in *any* child, and that child would be counted, with the incentive that counting more children will result in more funding.

I think, therefore, we cannot say with any assurance that the projected incidence of deaf-blindness is indeed two in every thousand children with special needs. We must do a great deal more analysis of prevalence using more clearly defined criteria. I think that projecting the incidence of deaf-blindness and holding states to try to identify the anticipated number of children is a dangerous practice without establishing such criteria. Tying the amount of funding a state is given to this number compounds the difficulty by encouraging slipshod practices in identification in order to bring more funding into the state.

A decade ago, we did not have a sophisticated system for counting children as we do today. However, I think we had in many individual states and regions, a better understanding of the children we were serving. These centers of excellence in educating those who are deaf-blind have been looked upon and emulated as the most effective model for serving children who are deaf-blind by countries around the world. The success of these centers was in large part due to a greater abundance of professionals who were in charge of state or multi-state programs under Section 307.11 who were trained as teachers of children who are deaf-blind. Today, there are fewer than a handful of states whose projects are being operated by administrators with knowledge

and background related to children who are deaf-blind.

In the absence of having trained professionals leading the effort, we have often focused our energies away from the specific needs of children with diagnosed vision and hearing losses into systems-change efforts that are very generic in nature. We have allowed funding designed specifically for children to be used for much broader efforts, which, in my opinion, supplants efforts which should be funded under state plans for the implementation of P.L. 94-142. It should be the responsibility of the Section 307.11 project to support these efforts by establishing a strong system of support for children who are deaf-blind. We need to develop central centers of expertise about the population of children, where people can come for information, training, advocacy, and support.

Looking back at how services to children who are deaf-blind have evolved in the 80s, the situation is analogous to efforts in consumer product marketing we saw during this same era. During this time, we saw our grocery store shelves lined with black and white "generic" packages which were advertised as the "best buy," giving us more for our money, and for a while we were all rushing to buy them. Then, we began to realize that the those generic paper towels were not quite as good as the name brand, and we would rather buy less of a high quality product than more of a poorer quality. With the limited financial resources we have available to us, I do not think we should be advocating for "false positives" in our identification of children. We should decide carefully who is deaf-blind, and target our energies in ensuring that these individuals have the maximum, highest quality services available to them.

Utilization of Census Data in Program Planning

In preparing talks, we have been taught to speak from that which we know, so I wish to talk a little bit about how, over the past 11 years during which I have been affiliated with the New England Center for Deaf-Blind Services, we have used our student data. At the Center we have kept rigorous identification standards requiring documented hearing and vision loss, and other detailed, child-specific information. Individual files are kept with diagnostic, educational, and social information that is necessary for consultants to have in order to develop plans for technical assistance and direct services. We felt it important to know who the children were, their etiologies, detailed information about their educational services, and their living situations. In planning services for this four-state region, these pieces of information were used as the cornerstones of all regional planning efforts.

In looking at population dispersion, we knew that in 1982 there were 29 sites where children who are deaf-blind received education, as opposed to more than 160 sites in 1992. In 1982 we were able, with available resources, to offer substantial services at the individual program level. The center staff, based at Perkins School for the Blind knew personally all of the children in each program, and had long-term relationships with administrative and teaching staff at each site. As services then became increasingly decentralized, and the numbers of programs and associated service providers became magnified, we realized the need to develop "experts" outside of the center who could have much easier access to children and programs and be a link with centralized training and technical assistance efforts.

Vic has shared with you the information required on the census form with regard to

age, etiology, and disabling conditions. With this information we can make projections about the types of information teachers may need and connect teachers, students, and families with common concerns. For example, we were able, with this central information, to identify where each student lives who has Usher Syndrome, and develop connections for training and support. We can see that now we are serving wider numbers of children with complex health care needs, and we are able to develop information and training specific to this subgroup of the population. We have also been able to link families of children with other very rare genetic disorders who have developed friendships and have learned a great deal from one another. I can cite many other examples of the usefulness of this information, but will not, due to limited time.

Summary and Recommendations

As we evaluate the strength of state or multi-state projects under Section 307.11, we must look much more closely at the process by which states are identifying children, and how their plans for delivering services are designed in response to the needs of the individuals. I am therefore suggesting the following:

- We should change the criteria by which Section 307.11 proposals are evaluated as follows:
  - The readers' guidelines should more thoroughly emphasize evaluation of how well-informed the project is about the children whom they propose to serve (i.e., what is their process for identification of children who are deaf-blind; how in-touch is the project with the specific subgroups of children who are deaf-blind; how aligned are direct services and technical assistance to the needs of individual children and families).
  - If funding continues to be distributed via an unofficial formula system, then Section 307.11 child count should not be a separate factor within the funding equation. It should rather be a component part of the proposal evaluation. This will alleviate any over-identification for the sole purpose of increasing funding.
- We should eliminate the categories of "unknown" and "not tested" on our census forms. Children could be identified as unknown or not tested within the body of the grant application; however, applicants should be accountable to identify how (by what process) they propose to gather more conclusive information about sensory loss.
- A task force should be developed, comprised of professionals with training in the education of children who are deaf-blind, consumers, and family members, to establish a more accountable system for identification.

This symposium will have major ramifications on services to children who are deaf-blind. I am hopeful that, through these recommendations, we may develop strategies to take a more qualitative look at what we are doing. We must not lose sight of those for whom the services are intended.

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FAMILY SERVICES: PARENT REPRESENTATIVE I

Mary O'Donnell

Abstract: During 28 years of working to improve services for those who are deaf-blind we have seen much progress in quality, diversity and delivery of services; yet, too many families are inadequately served. Today's parents need the following: a team of expertly trained professionals to work in partnership with them to help them make informed decisions; support (in-home help and monetary assistance for equipment); individual choices and flexible planning; respect from professionals for the entire family unit; a suitable array of adult service choices; and an emphasis on self-determination.

We have taken on a great responsibility as representatives of families of those who are deaf-blind to identify here our critical issues in anticipation of a brighter future.

As "senior" member of this panel, my charge is to present a historical perspective as well as our dream for the future. When our daughter, Sara, was born in 1964, the medical resources we accessed were baffled. The clergy was uncomfortable with our circumstances, and a few relatives and friends found Sara's circumstances so difficult and their ability to react so awkward that they withdrew from us. Fortunately, most family and friends were supportive. The human service delivery system and educational fields were a void. There were no resources, no literature, no systems in place to assist us.

Fortunately, many professionals were attracted to the field and began to develop a service delivery system, working very closely with families who were seeking the best possible advantages for their children who were deaf-blind. The children with Rubella and their families have been advocates and model program recipients for services for 28 years. It has been a long and difficult road to travel through infancy, childhood, and adolescence, only to find that adult services are an even bigger challenge to develop and access. The successes and positive results we've achieved along our road have been numerous and beneficial for all children who are deaf-blind and their families. However, there is still an enormous amount of work to be done in fine-tuning our services and making the best accessible to all.

Recently, I sat in on a focus group addressing present service delivery. I heard young parents tell of lack of medical resources when their baby was born, isolation, not knowing where to turn for help, going home to make hundreds of phone calls to find answers and direction, disagreement among service providers on who would take responsibility, dead end referrals, buck passing, uncooperative boards of education, and so on. The parents in the group had finally been able to access some wonderful supports and their children were enrolled in good programs. Good programs do exist close to their homes! However, the stress to accomplish this was enormous!

I was appalled, disappointed and yes, angry that, in spite of all the progress, mandates, entitlements, supports and developments in education we have worked so hard for in the past 28 years, young parents are having such difficulty accessing help. What happens to those children and families who don't have the skills of those in our focus group and don't live with the same proximity to services?

I've had opportunities recently to meet with parents from several states, as well as my own, and have asked about critical issues. Although it's not the "perfect poll with a 3% margin for error," the following were the issues of great concern identified by most.

- **Family support**, including in-home help and, when needed, monetary assistance for equipment and augmentative aids.
- **Focus** on individuals' capacities and respect for families.
- **Resources** to educate families to make informed choices and know the rights of their children.
- **Choice** and availability of high quality education settings.
- **Personnel preparation** that is more comprehensive, especially for direct care workers, teachers, and case managers.
- **Adult service development.**
- **Leisure time and recreation** opportunities and access for folks who are deaf-blind.

We have a dream! As soon after birth as the disability is identified, support is made available to all family and extended family members. This team includes informed clergy, a psychologist, and representatives of medical and educational service providers, as well as a peer parent.

The team will assist the family to identify the supports they need—spiritual, psychological, peer, medical, material, monetary, and so on, and enable them to access the help. Choices of in-home support, out-of-family home residences, medical services, early intervention, inclusion, neighborhood schools, specialized schools, segregated programs and so on will be identified and families will easily access information necessary to make informed decisions. Families will be trusted to make the best choices for their children. The focus will be on strengthening the family unit and coping skills. A family not functioning well is unable to process information, make wise choices, or take advantage of resources. Individual and family differences and uniqueness stemming from cultural, environmental, socio-economic status, outside obligations, and internal responsibilities will be respected. Too many professionals for too long have tried to impose their value systems upon clients and their families.

In our dream, no judgments are made, and no doors are closed since circumstances and choices may be different next year. As the child matures, he or she is included in the decision-making processes. Self-determination is encouraged.

A suitable array of adult services that may range from independent living and career opportunities to a very supportive community residence with an individualized day program, as well as supported living with family, will be options for families to access. Decisions will be dictated only by the individual's capacities and her or his family choice. Again, there will be no judgments, no final choices. Circumstances change.

In order for our dream to be realized, we need to make a few philosophical changes. The professional's role is to support, to educate, to offer choices and to develop and offer services of the highest caliber. Our personnel preparation is a key factor in success. We need to train personnel in a broad spectrum of service delivery modes to assist each individual to reach his or her potential in the environment most agreeable to those affected—the individual and the family. Capacities and quality of life are

enriched only when individual and family choices are respected and honored.

There can be many roads to the same destination. We are not all coming from the same place, so each of our journeys will be different.

The full realization of the dream, the destination we are all trying to reach, the critical issue, is the individual's happiness in a safe, productive environment where our person who is deaf-blind is respected, treated with dignity, and given the supports she or he needs to reach the highest potential.

Families are included all along the way in the decision making, always respected, and always given access to local, state, and national resources and networks as avenues for advocacy.

It is the professional's responsibility to see that the infrastructure of the roads the disabled and their families must travel is sound and that all the stops are state-of-the-art, well-staffed, well-equipped and the welcome signs are always lit and sincere—only first-class facilities available. Those who are deaf-blind and their families can then take the road from where they are, knowing there are no barriers or detours to prevent them from reaching their destination.

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FAMILY SERVICES: PARENT REPRESENTATIVE II

Ralph Warner

Abstract: Since parents must advocate for services for their children, they are often placed in stressful adversarial positions with professionals. Professionals need to be trained in how to work in partnerships with parents.

I am from Pennsylvania, and I want to thank everyone for allowing me to speak here today. A little about myself: I have a wife Candy to whom I've been married for 18 years, a son Ralph who is 16 years old, a daughter Jill who is 13 years old, and a son Adam who is 2 1/2 years old.

For the last six years I have owned my own business, manufacturing industrial machinery. I started this business with the help of my wife, in a small garage and very little money, so since the beginning I have had to devote all my energy and time to building the business. In the first three years we more than doubled sales and profits each year. After less than one year we bought a new large building and land where we are now, and many new machines.

Along with being happy about the way business was going, we were also happy about the fact that we were going to have a baby soon. Then in April of 1990, we had born to us a baby whom we named Adam. From that day on, things will never be the same for us. Adam was born deaf-blind and has athetoid cerebral palsy. Adam's five-week stay in the neonatal intensive care unit, where Candy and I and my other children spent every day wondering if Adam was going to live or not, was total devastation to my business and family life. We had no support or help from our families. A few friends helped as much as they could.

After we brought Adam home from the hospital we thought we should contact Pennsylvania School for the Deaf because he was profoundly deaf, and maybe they could help us. We were told by the doctors from the hospital that he should get physical therapy, occupational therapy, and speech therapies as soon as possible. The people at Pennsylvania School for the Deaf told us we should sign up at our local mental health/mental retardation office to get these services. So when we called and registered Adam they told us there was nothing for him until the following September. Pennsylvania School for the Deaf also told us that because of his blindness we should maybe contact Overbrook School for the Blind and so we did. Adam started getting vision therapy once a week from them and once a week we would go to Pennsylvania School for the Deaf. During that summer the staff at the Pennsylvania School for the Deaf and Overbrook taught my wife and me many things about deafness and blindness, but best of all was that the people at Overbrook told us about a deaf-blind conference for parents. Our entire family went to that conference. At this conference we learned we were entitled to all services for Adam now and that we didn't have to wait until September.

When we got back from the conference I called my legislator and asked for copies of all laws pertaining to disabled children. When I received these laws, as thick as they were, I read them over and over. Then I went to the state capital and started to sit in on all meetings that I could attend, that had something to do with these laws. When I became aware that Adam was entitled to services now, I went to the State Interagency

Coordinating Council and told the Secretary of Special Education and the Deputy Secretary of Welfare my story. I started to get services for Adam immediately thereafter. Even after this, however, I still couldn't stop learning about the laws because they changed so fast and, in many cases, the people providing these services for children did not know the laws either. After Adam started getting physical therapy, occupational therapy, and speech therapy, he still was not getting enough. He also needed vision, hearing, and deaf-blind programming. I found out he was entitled to those services also, so we fought for them until we got them. Over a two-year period we learned and fought to get Adam's initial needs met.

During this time I spent almost two, three, and sometimes four days a week in Harrisburg learning all about the laws and advocating for Adam. As a family we went to all conferences that we could find anywhere in the United States so we could learn more about deaf-blindness. We even went to physical therapy training so we would know if the therapy Adam was getting was good.

Because of all this lost time away from work, my business started to lose money. My wife no longer could work in the office and since I was gone all the time I lost almost $700 thousand dollars the first year my son was born. That year we had our car repossessed by the bank, and finally my wife and I both declared bankruptcy. Later, my business had to declare bankruptcy under Chapter 11 reorganization.

We had to do this not because of the high medical bills but because of the need to advocate for Adam. Knowing today all the things Adam has accomplished that every doctor and therapist said he would never be able to do, makes all the things right and well worth the hassles.

But, what about the people who can't do what we did? Maybe because they can't take off work without getting fired, or maybe because they are single parents. Where were all the people who could help us? When my other children went to school or needed help there was always someone to tell us what we could do or where we could go for help. We thought it would be the same for Adam, but it wasn't. I have thought a lot about this and I am not sure why this is but, since I have learned about special education laws and how to advocate for my child, I have decided to share this knowledge with as many other families as I can, so they won't have to go through as many hassles.

Two years ago I became President of a statewide parent advocacy group called SNAP (Special Need Alliance of Parents) and President of PPDB (Pennsylvania Parents of the Deaf-Blind). Since that time I have installed an 800 number at my office so people needing help can call me free. To date, I have travelled all over the state helping families at IEP (Individualized Education Plan) and IFSP (Individualized Family Service Plan) meetings get what they are entitled to. I have, since September, 1991, helped 67 families in due process hearings and have won all of them. In most cases, we were awarded make-up education in addition to the services needed.

In the State of Pennsylvania we have some of the best laws in the country having to do with early intervention and special education. Why is there still such a need to fight for these services?

As I reflect on all the meetings, I have come to understand that the system must change. At the rate of doing one due process at a time it will take a very long time to change, so along with parents advocating for their children, other things need to happen. In all the new laws, parents are to be equal

partners in all decisions made about their child's program. It is hard for professionals to start accepting this, because for years the professional knew what the child needed and told the parent what was best. Professionals, teachers, therapists, administrators, and doctors need to be trained in how to work with parents as partners.

In old laws, services were based on amounts of money available, today the laws are based upon the needs of children with no limitations based on funds. Of course, when these laws were passed there wasn't enough money budgeted to fund them fully. Administrators need to try to make a little money go a long way, and this ends up being a barrier parents come up against all the time. When all the new laws were enacted, there were not enough qualified teachers, therapists, and specialists to handle all the newly found eligible children. Typically, in these fields, professionals are not paid enough, and many end up leaving for better jobs. This results in high turnover rates and lack of continuity of services.

Laws need to be passed to serve these children better, but they need to be implemented from the bottom up and from the top down simultaneously, to prepare people for changes. I have been to many conferences where trainings were taking place for professionals, and many times I have heard them speak of all these new laws and how we need time to get used to them. Well, I am sorry, but I must speak as a parent. It is *all* new to us, but we can't take time.

As parents are beginning to be more educated about what they are entitled to, relations between parents and professionals are becoming more adversarial. If this growth of mistrust continues, it is going to become harder and harder to get parents and professionals to work together. Professionals must realize that parents are not being adversarial; they are just advocating for their children.

History shows laws and systems don't change unless parents advocate change. What professionals need to understand is that having to fight for our children's rights adds to the already very stressful lives of our families. Instead of adding stress, professionals should try to help alleviate stress.

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FAMILY SERVICES: PARENT REPRESENTATIVE III

Barbara Caudill

Abstract: Mainstreaming presents special problems for parents. Agencies and the public schools often are adversarial. Special equipment needed for school work is unnecessarily difficult to acquire, and academic progress is often at the expense of social relationships. Services that focus on the needs of the individual child should be available from the beginning of the educational experience.

It is a pleasure to be here today to present my thoughts about some of the issues surrounding the services offered to the families of children who are deaf-blind. I am the parent of an 18-year-old daughter, Krista, who is a senior in high school and who is deaf-blind.

When I became a parent, I never thought this event would change my life so dramatically. Like most first-time mothers, I was excited about the prospect of having a baby to care for and love. I had great dreams about the way life would be. I knitted baby blankets in green and dreamed some more. I dreamed of how we would have long talks about life; we would be close in spirit; we would discuss any problem; we would play; and we would laugh. This child would have plenty of praise and love. Nothing could limit this child. If, at that time, someone had told me that this baby was going to grow up in a world without sound and with darkness, I would have thought they were ridiculous. Not me! Not my child!

When she was born, there was no indication that Krista had visual or hearing impairments. Although the diagnosis of these two disabilities came in definite stages, I learned that Krista was both deaf and blind when she was two years old. I will never forget the doctor who diagnosed her visual disability. I was in shock when the bad news was presented to me. I said to the doctor, "What do we do now?" His reply was, "Go home and pray." Can you imagine the hopelessness I felt?

My first few months after learning about the extent of Krista's disability were torturous for me. I was very depressed, but still found myself having to care for this little mass of two-year-old energy. Memories are a blur from that time. My body felt as if it wanted to go into shock. I had so many emotions running through me. I felt as if I wanted to burst.

What I didn't realize then was that I was going through the process of grieving, although this particular grieving did not follow the same course or the period of mourning that we are familiar with. A more accurate term for mourning a severe disability is "chronic sorrow" because it is recurrent in different stages throughout the disabled person's life. In contemporary society this kind of grieving is often denied by others. It may even be considered a personal flaw. The expectation that is valued in the grieving person is to cope heroically and to get on with life. What often happens is that parents are so involved with caring for the young child, that they don't have time to mourn when the disability is diagnosed. Mourning occurs throughout the child's life. Developmental milestones of nondisabled peers such as walking, talking, entering school, and graduation may trigger grief.

Events that are significant to parents may also trigger grief. For example, I will never feel the same about hearing a beautiful piece of music that Krista will never hear, or seeing some of God's beauty in nature that she can never see. I try to describe these things to her, but no description can do justice to such events. At these times, I feel very sad.

Parents of disabled children are permanently changed by the suffering and grief. Lifestyles and relationships with family and friends are often altered to accommodate these significant changes.

I learned that a variety of things happen to the families, for example, being drawn together or torn apart, by the stress and strains of the disability. The disabled child's condition is often denied or not talked about by other family members such as grandparents, aunts, uncles, and friends. Family support is very important; however, in many family situations, it is nonexistent. This can cause strains in familial relationships, sometimes causing alienation of members.

What is needed here for these parents is support in the form of counseling or a support group for parents with grief issues, and familial or relationship problems. Currently, only a few states have any services of this kind available to parents of children who are deaf-blind.

Being deaf-blind is something that does not go away with time. The psychological problems can become more aggravated if help is not given at the onset of the disability. The parents and the child who is deaf-blind are not the only ones affected, this lack of support affects the entire family. Parents of disabled children are often so overwhelmed with the disabled child that siblings are not allowed to be children. The focus of the family is on the disabled child. Fulfilling some of the specialized needs of the child who is deaf-blind will help to take the focus off the child who is deaf-blind and put it back on the family unit. Consideration should be given to hiring parents of children who are deaf-blind to provide additional services to the families. These parents have invaluable knowledge, wisdom, and experience.

The equipment needs of the deaf-blind are very, very important. Their equipment needs can be very individual and unique. They can range from a simple adaptation to specialized Braille equipment that costs thousands of dollars. Although it is expensive, the equipment is a must so that the child who is deaf-blind can develop to his or her fullest potential.

A few vignettes will perhaps illustrate problems in these real-life experiences. The first example is that of a 14 year old boy who is deaf-blind. He needed an adaptation made to a regular visual computer keyboard, a matter of putting enlarger keys on the keyboard, which is considered a low-tech, low-priced adaptation. The mother tried to convince the school that there was a need for the adaptation. Finally, the school allowed the adaptation, but, at the parent's expense.

The next example is from my own experience. Earlier this spring, my daughter was promised training in WordPerfect. A few weeks before the training was to occur, I was notified that it had been canceled because of some scheduling problems. Training was finally provided for Krista in late August. To get to this point, I had to spend several hours weekly on the telephone or writing letters about this training. I finally had to request a meeting—one that lasted three hours—with all key players present. Again, this need was not a high-tech request. It was one that could be fulfilled at the agency, yet such a big issue

was made of such a simple request. Why is this still going on? Why do parents of children who are deaf-blind still have to beg and fight for these services? Services that are rightfully theirs?

My dream is that parents won't have to be placed in an adversarial position between the school and agency that is working with the child. Another dream is that equipment needs, no matter how expensive they may be, will be seen as a tool for the child who is deaf-blind in either the special education or the regular educational system. These tools can be used outside the educational system for integration into neighborhoods and communities for everyday living and communication with people.

At the beginning of my talk, when I spoke of my dreams, I was particularly thinking about this one. In Krista's early years, I truly believed that she could be taught to fit into the mainstream of life with those who are not disabled. I still do believe this is possible, but I have modified that dream a little. Now, I know that the only way that she will do this is with adaptive equipment.

Krista is currently a senior in high school. She is in the top one-third of her class academically. She is fluent in Spanish. To me, this is an astonishing accomplishment. The only reason Krista has been able to be competitive in her academics is because she has had adaptive equipment available to her. Without it, she would be very limited, and, I am sure, she would not have been able to achieve as she has in the intense academic program that she is in. Krista has had a person-centered approach for her equipment needs. Every disabled person should be considered on an individual basis, not only in a school program, but throughout their lives to ensure that their individual needs are being met.

Although Krista has been very successful academically, the social situation has not been good. As she made the transition to middle school, Krista was not accepted as she once had been. As we are all aware, those middle school years are tough for any kid. Peer interaction, being with the popular group, and appearance are main priorities for most kids.

I hoped that gradually the situation would improve, but it hasn't changed that much. Krista went through some pretty difficult times. She became despondent. She finally decided that school would be a place to learn and that she would look for friends outside of that setting.

The concerns I have about inclusion of disabled children in the educational system are centered around the experiences I have just shared with you. A choice had to be made about Krista's academics versus social isolation. This is a decision that not many parents are asked to make, and I ask you to think about how difficult that decision was for me. The choice that was made was to pursue excellence in education, and the social interactions suffered. I feel sad that nothing will ever make up for the fact that Krista did not have the opportunity to be a part of girl gossip, boyfriends in schools, hanging out with friends, or proms. I can't tell you the pain that I have felt.

The educational system needs to address these issues if disabled children are going to be successfully included in the regular educational system. I would like to see the day when this is a reality—a day when our disabled children and their differences are accepted by their schoolmates. That will be a day when parents of disabled children are not asked to make choices like the ones I have had to make.

I have never met a parent of a child who is deaf-blind who doesn't have some fear of

the future. They ask what will happen to the child when they are no longer here. Will he be put into an institution? Will there be money for medical needs? Who will be able to care for the child and provide for him the way they do?

It is uncommon for an adult child to live at home indefinitely. Yet, I see a large number of deaf-blind adult children living with their parents after their schooling is completed. Reasons for this practice may be the lack of housing for the deaf-blind or parents being unable to let go of their adult children. Many times, however, parents have had to continue to be advocates for their children.

The medical aspect of the disability may be one a parent worries about. The Medicaid system in our country is one we should all be concerned about, and is particularly worrisome to those parents whose children are medically fragile.

The financial situation of the deaf-blind person causes worry also. If the person is unable to work, Social Security Insurance coverage is minimal. And, for those parents whose children are able to work, there is still the problem of availability of jobs. We all know how high the unemployment rates are in the United States.

Again, I think that what is needed are person-centered services from the beginning of the educational system, throughout vocational rehabilitation services, to whatever else is necessary for the future of the individual. Some of this should already be in place within the system, but the truth is it's only happening for some, and never on a consistent basis.

Sometimes people ask me what it is like raising a child like Krista. This question is a difficult one for me to answer because it elicits many feelings. Krista and I have a very special relationship because of her disability, although this relationship is different from the one I expected when I was dreaming and knitting that green blanket so long ago. The role of motherhood that I envisioned then has been altered. We do not have the luxury of having leisurely conversations that I had thought we would have. Much of our time together is spent explaining the world or situations to Krista.

We cannot enjoy a movie together or do many other activities. I often feel exhausted from interpreting. I sometimes feel guilty because Krista misses so much, both visually and auditorially. All of these things are true. What makes it all right is that there is a special joy and love that I hold for this wonderful person I have the honor of calling my daughter.

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REVIEW OF THE LITERATURE

H.D. "Bud" Fredericks

Abstract: The majority of the literature about parents of children who are deaf-blind appears in the early and mid-70s. The area of concern to parents that is reported most frequently and consistently from the 70s to present day is the transition of their children from school to adulthood. On the other hand, there is a paucity of published literature about parental opinions regarding P.L. 94-142 and the Individuals with Disabilities Education Act. With one notable exception, professionals surprisingly have not focused their research efforts on the views of parents regarding the least restrictive environment concept in education and the movement to inclusion.

Parameters

Family Services encompasses a broad range of foci. Consequently, we examined the literature in the field across many dimensions to ascertain how families of children who are deaf-blind were discussed. We limited our review to documents published since 1975. Admittedly, this is an arbitrary cut-off date but it coincides generally with the advent of P.L. 94-142, at which time parental influence in the educational process was formally recognized by the federal government. The years following 1975 should have been a time when both parents and professionals were rethinking the part that parents play in the education of their children who are deaf-blind. We expected a plethora of articles focusing on parents and their needs, but such was not the case. In fact, in some areas, the paucity of published writing is cause for concern.

We departed in one area from the 1975 date. As we sought writings about parental stress associated with parenting a child who is deaf-blind, we found no works published since 1975. Therefore we have cited three works published in 1972. We recognize that educational, medical, and support services have changed dramatically since 1972 and perhaps the same stresses do not exist today. Therefore, these citations may not be relevant in our current culture.

In the extant literature there are many articles written about parents of children with disabilities without specification of the disabilities. We did not include those articles in our review even though some of those writings may pertain to parents of children who are deaf-blind. However, because the purpose of this symposium was to provide state-of-the-art information, we concluded that any literature reviews should also be so focused. As we shall see, this narrow approach serves a salutary purpose in that it indicates a major need—more attention in professional writings on the needs and perceptions of parents of individuals who are deaf-blind.

Early Intervention

Two articles focused on the parental role in early intervention. Wolf (1980) described the need for family home services for young children who are deaf-blind. In discussing the characteristics of those services he emphasized the need to teach parents how to communicate with their young child and to orient the child to the home environment. Michael and Paul (1988), in an article that examined issues regarding early intervention with infants who were deaf-blind, recommended that parents and other family

members be involved as early as possible in the intervention process with assistive devices and professional support.

School Years

A search of the literature uncovered only one article that focused on parental involvement in the school years (Giangreco, Cloninger, Mueller, Yuan, & Ashworth, 1991). The authors surveyed the parents of 28 students who were on the Vermont registry. Parents indicated frustration with dealing with schools because of the large number of professionals with whom they had to interact. Moreover, they felt that there was a need for better coordination and communication among the professionals. Most parents viewed themselves as the coordinators of services.

Giangreco and associates (1991) questioned parents about their preferences regarding integrated or segregated services. Integration or segregation was not the issue. Parents' satisfaction with educational placement was correlated with the extent that teachers and staff demonstrated a genuine concern for the child by working hard to make the school experience positive and meaningful. Parents of children in segregated settings and parents of children in integrated settings both felt that changing their child's educational setting would be negative. Both groups of parents listed the same reasons for opposing such a change: The child would "regress, be neglected or overlooked, be exposed to undesirable behaviors, not receive enough appropriate stimulation, miss his or her classmates, lack needed learning opportunities, and that the change would be disruptive" (p. 20). A search of the literature uncovered six articles that discussed parental involvement in the school years in the transition area.

Transition

Burley (1978) highlighted the need for parents of children in school to think about the needs of their children as they approached adulthood. Covert (1987) summarized the need for family involvement in transition.

Providing services to this population must take into account parent/family needs, preferences, desires and value systems. Parents and families need to be involved to enlist their support as well as their expertise, in all aspects and at every level, in providing comprehensive services for individuals with profoundly disabling deafness and blindness. They need to be involved in decisions regarding the education and training of the individual with disabilities, as well as in the placement of community services. In order to strengthen the parent/family role, parents need to be provided with full information on options and choices open to them and to the disabled child. Parents/families often lack information on the range of services, including community based services that are, or can be, available to them. Thus . . . parents frequently choose the more traditional, familiar services. (pp. 152-153)

Everson and Michael (1992), in discussing the formation of inter-agency collaboration to achieve high quality transition, make a strong case for parents being active members of such inter-agency transition teams. They indicate that parents provide (a) a good base of knowledge about persons who are deaf-blind and the services available, (b) personal dedication, (c) the ability to maintain the focus of the group, (d) a liaison to other parents, and (e) advocacy in political arenas.

In the survey of 28 parents conducted by Giangreco and associates (1991), parents identified a number of postschool activities including supported employment, volunteering, continued education and

training, and leisure activities. Some of the parents did not consider that employment was a viable option for their child. These same parents wanted their child in the future to live in a home and did not want their child to live in a congregate facility such as a nursing home, large group home, or institution.

Leisure, Recreation and Social Interactions

Only one reference focused on the parental role in leisure activities for the child who is deaf-blind. Ryan (1987) indicted that finding age-appropriate recreational activities for the child who is deaf-blind is a significant challenge. She discovered that she could not rely on the natural supports that may be available in the community but had to hire a companion to assist her child in obtaining age-appropriate leisure time activities. Giangreco and associates (1991), in a survey of 28 Vermont parents, reported that they considered it vital to establish and maintain for their child a social network of people who care. When asked about social interactions with peers in school, parents expressed pleasure with those interactions although they were unsure that their child gained anything positive from the interactions. However, they were confident that the nondisabled child "got a lot out of it" (p. 19).

Parent Training Needs

We have not included in this review a listing of materials that have been developed to train parents. We did, however, seek out writings that discussed parent training needs. Wolf (1980), as previously cited, indicated that parents of young children needed home services that taught them how to communicate with their young children and how to teach orientation and mobility skills. Kershman, in two articles published in 1982, reported the results of a survey to determine the needs of 310 parents of children who are deaf-blind. The results indicated that parents listed as their greatest needs legal issues most often related to school services, curriculum and instruction on how to use that curriculum, and knowledge about the child's disabling conditions. The next most prevalent needs were behavior management, affective adjustment, family roles and interaction, and health care and maintenance. Kershman also found that the training needs of parents differed based on the following three factors: (a) the frequency of contact with their children with sensory impairments, (b) levels of education of the parents, and (c) different income levels.

Hostler (1987), examining the health needs of the family, indicated that there was a great need for psychosocial service for the family. She focused on the extant literature regarding parents of children with disabilities and extrapolated findings from that literature to parents of adults who are deaf-blind. In essence, she advocated that the health care system had to assist parents to cope with the everyday stresses of having a child who is deaf-blind.

Andrews (1989) focused on the needs of young children who are deaf-blind and their parents, emphasizing the need for communication and orientation and mobility training for both parents and children.

Parental Stress

All parents experience stress at some time in the raising of children. Parents of children who are deaf-blind may experience stress idiosyncratic to having a child who is deaf-blind. Three authors focused on this subject. It should be recognized that all of these writings are approximately 20 years old, and the thoughts expressed by them may not be relevant for today's society. Yu (1972)

examined the medical, economical, emotional, and professional factors that added stress to 13 families with children who were deaf-blind as a result of rubella. She cites that frequent medical visits and hospitalization create significant stress on parents. In at least one case she cites the economic hardships that these medical expenses caused on the family, thereby adding to the stress already experienced by the medical condition of their child. Emotional factors leading to stress are (a) initial shock of learning that the child is disabled; (b) difficult behaviors exhibited by the children; and (c) lack of affectionate behavior exhibited by children to their parents. Conflicting professional advice caused some parents in the sample to be stressed. Yu recommended that professionals develop plans of actions towards mutual goals to help families with children who are deaf-blind.

Torrie (1972) describes the emotional problems and behavioral patterns of parents who have children who are deaf-blind. She cites stress being caused by the behavior of the children, the isolation of the child from the family because of communication difficulties and the frequent health crises experienced by the child. She describes the parent of the newborn as one who is mourning and encourages professionals to be sensitive to this mourning and to help the parent develop "defense mechanisms" because, until they are developed, the parent will not be able to help the child.

Hammer (1972) postulates that parents of children who are deaf-blind frequently have common needs and experience definite critical times of stress as their child matures. He identifies those critical times as follows: (a) at birth or upon suspicion of disability, (b) at time of diagnosis and initial treatment, (c) as child nears age for school placement, (d) as child nears puberty, (e) as child nears age for vocational planning, and (f) as parents age and realize that the child may outlive them. He indicates that parents need emotional understanding and support, information and facts, a greater degree of active participation in habilitation planning, a self-image of themselves as competent and participating community members, an understanding of their role in the habilitative process, and understanding of present and future expectations for the child with disabilities.

Two papers dealt with the professional's role in alleviating the stress experienced by parents of children who are deaf-blind. Both Mills (1979) and McWilliams (1979) discuss the role of the professional counselor in providing services to families that have a member who is deaf-blind.

Parental Expectations, Perceptions, Concerns and Needs

We expected more authors to have devoted energies to these aspects of parents. Very few did. Fernandez (1980) introduced a study about the concerns of parents with children who are deaf-blind but presented little data. Wolf (1980) as part of his studies determined that parents of children who are deaf-blind were very pessimistic about the future.

Perhaps the most comprehensive survey of parents of such children was conducted by Vadasy and Fewell (1986). In 1985 they surveyed 92 female guardians of children who were deaf-blind who were served in the Deaf-Blind Treatment and Evaluation Center at George Peabody College for Teachers between 1970 and 1978. A total of 41 families returned the survey. The survey not only ascertained information about the parents but also about the youth.

When asked where they expected their child to live as an adult, 24 indicated that their

child would live in the parent's home, 6 indicated the child would live in a group home, 5 thought their child would live in an institution and one thought their child would live in a foster home. Mothers were asked if they had made any plans for their child in the event of the parents' death or disability. Twenty-four had made no plans. Because these youth were at least 16 years old at the time of the survey and would no longer be eligible for special education services, Vadasy and Fewell (1986) asked the parents if they thought their child's needs could be met in programs that serve people with other types of disabling conditions. Twenty-six mothers felt that their children needed special services that were specifically planned for people who were deaf-blind. Six mothers felt that their children could be served in programs that served persons with other disabling conditions.

When mothers were asked to name three things that would have helped them to care for their children, 11 mothers desired more family support, 5 mothers wanted supplemental income, 4 desired a day activity center, and 4 needed more parent training. Special education was selected as the second most desired support as well as the third most needed support.

At the time of this survey 54% of the parents had children who were living in institutional settings and would have to take their child back home with them when the child turned 21. Kershman (1982) indicated in her surveys that parents who have less than monthly contact with their child are in greater need of parent training than those who see their child more frequently. Parents surveyed by Vadasy and Fewell (1986) recognized this need.

Giangreco and associates (1991) also surveyed parental perceptions, focusing on 28 Vermont parents. The results of this survey have been reported under previous sections of this review. The survey also reported that parents indicated that they were uncomfortable and avoided long-range planning for their children because "it's too big an unknown" (p. 19). Parents quite frankly admitted to fear, but they also perceived professionals being afraid to admit that they did not know something. Parents longed for professionals to be honest with them.

Parent Advocacy

Griffing (1976) discussed the role that parents play in policy making at all levels and encouraged parents to use their knowledge and become involved to influence decisions within the bureaucracy and legislature. He emphasized the importance of parental input.

Everson and Michael (1992) and Rachal (1992) recognize in their writings the important role of parent advocacy. They focus on parents as members of transition inter-agency groups. Rachal indicates that parents are often the catalyst for moving such groups forward. Moreover, parents can do things that agencies cannot do in that parents can lobby public officials without any constraints.

Siblings

Only one article was located about the effects on siblings of a child who is deaf-blind. Banta (1979) indicated that there were effects on siblings. In some cases siblings felt neglected; other siblings took on a role of caregiver. Although data were derived from a small *n*, Banta concluded that siblings may suffer even greater effects than parents and that even well-adjusted children can have negative feelings towards their sibling with disabilities and/or their parents. Normal siblings do not feel preferred. In

fact, they are often expected to achieve more.

Discussion

The majority of literature about parents appears in the early and mid-seventies. This literature was developed as a result of meetings conducted by regional centers. During the late seventies and early eighties there was a dearth of writings about parents of children who are deaf-blind. One might hypothesize that this was a function of the breaking up of the regions into a system of service delivery through individual states and consequently a lack of focus on the concerns of parents during these transitional times. We see in the middle eighties a resurgence of writings about parents, but the amount of research and reported studies is woefully inadequate.

What is of particular concern is the total lack of information from parents of children who are deaf-blind about the quality of education for their children. What was the effect of P.L. 94-142 and IDEA on children who are deaf-blind as perceived by the parents? How do parents perceive their state's efforts to provide early intervention services? What effect have these services had on parents of such children?

It would be interesting to know how the passage of federal laws regarding education and early intervention has affected the stress levels of parents with children who are deaf-blind. We could locate no published studies that focused on that question. It should be a research area of high priority.

One of the areas that received a fair amount of professional attention was parental involvement in transition of their children from school to adulthood. In a number of studies (Burley, 1978; Fernandez, 1980; Giangreco et al., 1991; Vadasy & Fewell, 1986, and Wolf, 1980) parents voiced concerns about what will happen to their child when the child reaches adulthood. This was by far the most often repeated concern of parents. It is encouraging to note the recent emphasis on this concern. Covert (1987), Everson & Michael (1992), and Rachal (1992) focus on the role that parents play in transition and the importance of including parents in planning and implementation of services. It is interesting to note that these authors were able to devote effort to this area through the support of the federal government.

However, despite this one glimmer of encouraging focus on the role, needs and importance of parents, we see professionals generally not devoting energies and research resources to parental concerns and needs at the school and early childhood levels. Only Giangreco and associates (1991) focused on parental perceptions of education and then, only with a small population and in a state that has a history of high quality integration. Surveys across states are needed to gain an accurate picture of parents' perceptions of education in the area of P.L. 94-142 and IDEA. The federal government through its initiatives provided an emphasis on transition-aged youth and their parents. Perhaps it is time for the federal government to focus on parents of younger children who are deaf-blind in the same manner.

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FAMILY SERVICES: REACTION

Therese Rafalowski Welch

Abstract: Both families and service providers need to learn how to work together. Adults who are deaf-blind and parents of children who are deaf-blind are important resources and should be enlisted to provide information and support to families, especially at the time of diagnosis. At all stages, counseling and support groups for the entire family are essential. We need training programs to teach parents how to facilitate communication among all family members. Most of all, professionals must learn to listen to families to ensure that programs are truly family centered

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We have witnessed many significant changes in services in our field since funding for services to children who are deaf-blind was first established. There have been changes in educational, vocational, and housing options and, to a great extent, these were driven by changes in federal and state legislation. Enhancing the role of families in program design and decision making has been at the core of much of this legislation. We want to believe it is realized in our practices.

It is very disturbing then to listen to the accounts of our panelists and hear that, according to their personal experiences of trying to acquire services, things have not really changed over these past 30 or so years. We know too that this same message would be echoed again and again by families across this country.

We have to ask ourselves why we have missed the target. Why do families continue to feel that they have to fight or beg for services, or resign themselves to the designs of others who claim to be more knowledgeable or who simply control the supply of resources? And if parents like our panelists who are articulate and enterprising and active advocates say that their requests are too often not met or met only after considerable struggles, consider what happens with parents, who for a variety of reasons, may not be as outspoken or persistent.

Our vision must include the decision and the means to change this, to move us much closer to the target—much closer to what has been our intent—to support families. I would like to suggest a few points from which we can start.

The panelists spoke of the lack of and need for partnerships. Many of us here have spent years on planning teams and attending meetings for Individualized Educational Plans (IEPs), Individualized Family Service Plans (IFSPs), and interpreter training projects (ITPs). The coming together of service providers with parents and consumers at these meetings may well hold merit, but merely talking together or meeting together regularly does not automatically make a partnership or a team. A true and effective partnership requires a commitment to collaborate and negotiate; to clarify roles, responsibilities and values; and to agree on how decisions are made and how follow through will occur. Both families and service providers need assistance and training in this area. We need to look closely at successful partnership and team models and institute these practices. We must learn together how to be partners, how to work interactively—not with families and service providers in segregated audiences.

For too long, we have been teams in name only.

We also have to give more than lipservice to family priorities. For example, the pre-packaged IEP prepared by service providers, including only those services that the district or program currently endorses and funds, and awaiting merely a signature by a parent or consumer, is still far too commonplace. In these situations, parent or consumer input is more often viewed as a challenge to professional expertise and program authority than as a valued contribution. It is certainly not viewed as the foundation for developing program services. Our vision can and must look vastly different from this.

Regarding this notion of "challenge" as related to educational services, the panelists noted how they feel placed in an adversarial stance against service providers. Ralph Warner spoke of how often he felt compelled to use due process procedures to get needed services for his son and others. We must find better ways to settle differences. I would like to read a quote from a current text on family support:

Current policies that promote the use of due process of the resolution of service provision disputes often create a climate of competition between parents and educators, and prevent the development of collaboration that is essential to the desired home-school partnership outlined in legislation. This trend in adversarial processes could be countered by a new policy that stipulates mediation and problem-solving strategies as procedures of choice for disputes between service providers and parents (Walker, 1989, p. 117).

Our vision must incorporate such a policy. Truly successful settlements should unite all parties as never before. They should not divide them.

Let us turn to other issues. Information and support for families are perhaps never more important than at the time of diagnosis. Those first words to parents have such a profound impact. One parent reflecting on the time of her son's diagnosis said, "That first message stays with you and haunts you. You are always worried that those things that you later learn aren't true could still happen—even after you know better." The trauma of the diagnosis is further compounded for parents by a lack of information, or misinformation, and little or no support. Experienced parents, adults who are deaf-blind, and service providers together must strengthen their links with the medical community—form true partnerships—to ensure that families do not leave the hospital and fall into a void. Joyce Ford very eloquently addressed the state and multi-state project directors in October and said that, for three years following her son's diagnosis, she was alone. She said that she did not know the term "deaf-blind," she did not know anyone who was deaf-blind, and she did not know anyone who knew anything about people who are deaf-blind. Information and support have to be readily available before there is even any recognition of a "deaf-blind" identity. We cannot take away families' pain, but we can offer much more complete information than simply the all-too-standard litany of what your child will never be able to do, or what your child will lose, and certainly more support than, "Go home and pray." First impressions are very powerful. A family's first impression of service provision should be very positive; it should instill confidence and not cause further anxiety.

Another key component of our vision must be the easy availability of family counseling and related services that address general family concerns and those specific to having a family member who is deaf-blind. We cannot hear families speak as our panelists

did of "devastation," "how my life was never to be the same," and "chronic sorrow," and believe that counseling and support groups are not essential support services for families. This is not to say that funds from state and multi-state projects under Section 307.11 should cover all such costs, but we must help secure such services for families of children who are deaf-blind and ensure that funds are used to assist with the establishment of services, train personnel, refer families to skilled counselors, and meet emergency needs.

We must also ensure that our services are truly family services. It seems we often substitute the term "family" for "parents." We are only just beginning to acknowledge and address needs of other family members, as well as consider the concerns of nontraditional families. In particular, we need a very strong emphasis on sibling support. Families and those working with families are very familiar with sibling issues of neglect, jealousy, anger, and guilt. I know from personal accounts how frighteningly desperate sibling situations can become. There is an important organization that was rather recently established to help the program better address sibling issues: the National Association of Sibling Programs. We need to be an active part of that network. We also must consider the special needs of siblings beyond the school years. Adult siblings may have to assume new responsibilities for their brothers or sisters who are deaf-blind and have multiple disabilities when their parents are in some way incapacitated. Imagine trying to deal simultaneously with possible care arrangements for dependent parents and siblings. Access to services and support should be readily available to family members throughout their lives.

The umbrella issue for all of the concerns the panelists and I have attempted to address, and the real heart of our vision, is *listening to families*—trite as it may sound—*listening to families*. In September, I attended a parents' workshop sponsored by the Helen Keller National Center Technical Assistance Center and the Hilton Perkins Program. About 50 parents attended. At the workshop I asked parents to write a response to the question, "What are three things you would like to tell service providers about working with families?" Usually the first response, and always included as one of the responses, was, "Listen to us."

In our preparations for this section of the symposium, Bud Fredericks conducted a thorough literature search regarding parents and families of children who are deaf-blind. It was very telling to learn how little he found and that the majority of pieces were nearly 20 years old. The absence of such literature speaks loudly about our priorities and reflects on a larger scale what families are saying about not being heard. This too must change. I would like to suggest one area in particular for special study and response—the needs of single parents, especially single mothers. I am certain that a careful examination would show that these parents face alarming obstacles and tremendous stressors in trying to establish and maintain the delicate balances of their families. I hope such a study would result in a call to action for all of us.

Earlier I spoke of parents, adults who are deaf-blind, and service providers working together to improve families' experiences at the time of diagnosis. I would like to make appeals to all three groups to consider some key ways that I believe we, with a family focus, can assist one another, mutually benefit from our actions, and ultimately better respond to children's needs.

First, I appeal to adults who are deaf-blind. You have a great deal to offer families. Please reach out to the families of children

who are deaf-blind. If you have group meetings, arrange times when you invite families or individually make contact with families. You can get in touch with the coordinators of services and any parent groups, and let them know you are willing to meet with families. Ask the coordinators to inform families that there are adults who are deaf-blind who will talk with them. You can be invaluable resources for families. You make powerful allies.

I appeal to families. Early childhood literature notes how parents are their children's first and best teachers. Please be their first and best teachers of communication and language, especially sign language. Don't let children who are deaf-blind become second-class family members because others in their immediate family have not learned to communicate with them, or do so minimally, or rely on one parent to always be the interpreter. Make communication skills the priority in your home, just as you want them to be in your child's instructional programs. Your relationships are the most important.

Finally, I appeal to service providers. Let us make sure our programs are truly family centered. Let's involve families in every component of our programs—especially in the design and delivery of services. No more token representation. Let's make sure our programs are accessible to all families and all family members. We should be able to answer affirmatively to such basic questions as these: Can all families in our programs call us without incurring long distance charges? Are our working hours and meeting times flexible enough to suit family schedules?

In closing, I want to say that clearly we need to make changes in many of our systems to better respond to families. But we fool ourselves if we think that the solutions are systems functions only. It is in those personal, one-to-one relationships that we really come to know what families want and need. It is those personal partnerships that will sustain us and even allow us to prevail through any systems failures and will surely drive our desires and efforts to continue to improve.

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PSYCHOSOCIAL SERVICES: PRESENTATION

Harvey H. Mar

Abstract: Current practices in the delivery of psychosocial services and their effectiveness in addressing certain aspects of social and emotional well-being—social relationships, management of undesired behaviors, and counseling and related mental health services—are reviewed. Recommendations are to: (a) involve community resources such as medical and mental health centers in our education and training endeavors; (b) develop integrated models of mental health assessment and care; (c) eliminate the territorial mindset that exists in psychosocial services; (d) invest money and energy toward creating better generalists (rather than specialists) among our service providers; (e) lobby our higher education institutions to better prepare psychologists, social workers, counselors, psychiatrists, and therapists; (f) support efforts by family members to educate medical, mental health, and social service professionals; (g) target the neighborhood, worksite, and other public domains as environments for our programs; and (h) develop a data base of unique issues, diagnostic concerns, and effective treatment strategies.

Introduction

Over the past several years, many critical psychosocial issues have surfaced in our professional conferences and literature, sometimes causing great anguish to people in our field. We have grappled with what terminology, if any, best describes the diverse group of people who are deaf-blind, an issue that draws close to the core of individual psychological identity. We have argued whether or not it is inhumane and unethical to use aversive or noxious stimuli in order to protect children from causing serious harm to themselves or others. We have debated over what does or does not constitute normal intelligence, social competence, or appropriate behavior when a person has dual sensory impairments.

Obviously, our struggles with these issues go well beyond our symposia and papers which, like this one, present only snapshots or abstractions of very real psychosocial problems and dilemmas that our community—people who are deaf-blind, family members, friends, and professionals—confronts daily and over a life course. Each of us can recount, undoubtedly with great passion, story after story in which the psychosocial needs of a child, adolescent, or adult who is deaf-blind have been, or continue to be, unserved or unfulfilled despite all the available philosophy, knowledge, experience, services, and technology. Thus, in reviewing the state-of-the-art of psychosocial personal health, we might do better to think not only of what we know, do, and understand about the psychosocial issues that pertain to individuals who are deaf-blind, but also whether and to what extent this information and our actions actually serve to make real lives better. In other words, we should not just ask, "What *is* the state-of-the-art?" but, beyond that, "Is what we know making a real difference?"

This paper focuses on what our current practices are in the delivery of psychosocial services and how effective they are in addressing several critical issues pertaining to social and emotional well-being. Although for each issue I will highlight our accomplishments, effective practices, and promising directions, I also wish to identify some of the gaps in our current efforts to

meet psychosocial personal health needs. I will use the term "reality gap" to describe the difference between "state-of-the-art," or what, in theory, we should be capable of doing given our current knowledge, and "state-of-the-practice," or what, in reality, we actually do or accomplish. A reality gap is the difference between the outcome we aim for and the result we obtain. It refers to the difference between a "best practice" as idealized and the degree of real and significant change in one's quality of life that can be measured or observed after the practice has been implemented.

A second aspect of this paper is an effort to articulate a vision of what I hope is the not-too-distant future, and it is based upon several premises. First, we need to think about *why* these gaps in the delivery of psychosocial services exist so we can take specific steps to close them. Gaps exist because we don't have the "best practice" or service, we don't use what we have very effectively, or the "best practice" is too simplistic or abstract when we apply it to real and complex problems. Our priorities of the future should start with making sure we effectively address the priorities of today. Second, we need to do some "blue-skying," by which I mean dreaming or fantasizing about the psychosocial models, services, concepts, supports, systems, and even service providers that we wish existed. This may entail viewing the issues and problems we confront with new perspectives. Third, we need to interpret these dreams, not in the Freudian sense, but to identify the problems and questions and priorities we have yet to address. What will be our state of the art in 20 years?

Before discussing specific psychosocial issues, I would like to set the stage for thinking about reality gaps with a personal example. For the past eight years, I have been providing counseling to a young man, now in his 30s, who is deaf-blind and mildly mentally retarded. He was born with Congenital Rubella Syndrome and attended special schools all of his student life. He lives in a residence with other people who are visually impaired or blind. In spite of the severity of his dual sensory impairments, he independently navigates the subways and streets of New York City. He has special interests in heavy-metal rock music and electronics. When we first met, he was employed in a sheltered workshop. His "training" consisted of learning to package goods like ballpoint pens, pantyhose, and plastic utensils. He once brought home a paycheck for 50 cents—his wages minus all of the penalties he accrued for being late or falling asleep on the job that week. (He had the check mounted and framed.) He, his family members, supervisors, trainers, counselors, and service providers have worked together to identify and address many serious psychosocial and health concerns over the years, including his erratic sleep pattern, excessive daydreaming, depression, chronic lateness, lack of friends, and harmless, but poor, social interaction skills and behaviors. As a result, he became the beneficiary of many of the "best practices" we could implement: two years of training with skilled counselors in a supported employment program earning minimum wage; high-tech sleep studies; ongoing health care from a consistent, sensitive, and well-integrated team of service providers; a positive behavior management program to improve his ability to maintain a schedule; an increased menu of social and recreational activities; and eight years of supportive, individual counseling. So why does this man today work in one of the few remaining sheltered workshops in the city, earning $14 a week? Why are his only social outings on weekends with his parents? Why have the daydreams intensified into delusions? Why haven't we made a real

difference with all of our practices, programs, and interventions?

The answers, which I do not profess to have, are probably as complex as the potential solutions. My suspicion, however, is that the *real-life outcomes* of the psychosocial services and programs we provide may often be short-lived, incomplete, or of limited scope relative to what is possible or to what we aim for. At the same time, I am of equal conviction that our conceptual frameworks, philosophies, model programs, and "best practices" are, in fact, fundamentally sound, and that they must continue to guide the delivery of services. Hence, my initial objective is to propose that we do have "reality gaps" in both our services and our outcomes which we must first recognize, then consider why they exist, and subsequently deal with if we are to make headway either toward solving real psychosocial problems or extending our positive outcomes.

This paper will broadly survey critical issues which have to do with positive psychosocial supports for children, adolescents, and young adults who are deaf-blind. The issues are grouped into three broad categories that reflect the major forms of intervention and service to promote psychological health and welfare: support for the development and maintenance of social relationships; management of undesired behaviors; and counseling and related mental health services. I will state up front that my personal experience is very much biased in the direction of students who have cognitive disabilities, often severe. Some of this bias will probably leak out, but it is not my intent to give short shrift to the important psychosocial concerns affecting all individuals who are deaf-blind.

Social Relationships

We start with the broadest and, arguably, most important psychosocial concern—social relationships. Beginning with our first concepts of mainstreaming, we have advocated the increased inclusion of students with disabilities in school and community. We have observed, however, that even in integrated settings, children and adolescents with disabilities spend more time alone, have more disagreements, experience more rejection, are less occupied in cooperative or constructive work and play, and engage more frequently in regressive or problem behaviors than their nondisabled peers (e.g., Guralnick, 1990; Odom, McConnell, & McEvoy, 1992; Skellenger, Hill, & Hill, 1992). We also know that job retention among adults with disabilities has more to do with social skills and social competence than the actual ability to perform tasks (Park & Gaylord-Ross, 1989). Thus, parallel to the school and community integration movement, our priorities have also begun to focus on "the ultimate product of integration," namely, increasing the participation of learners in meaningful social relationships with their peers (Haring, 1991).

Social Isolation

Persons who are deaf-blind are especially vulnerable to being avoided, socially isolated, or excluded from interactions because their receptive and expressive communication modes may differ from those around them. Their social networks may be very small or limited relative to those of peers. We have also observed that more interaction occurs between teachers and students than between students who are deaf-blind and those who are not deaf-blind of the same age even when both opportunities exist. But we are just beginning to recognize the life-long psychosocial impact of such differences. The failure to establish meaningful social relationships eventually

leads to: (a) greater dependence on family members or care providers for the majority of social and recreational needs; (b) a higher incidence of behavioral or emotional difficulties including, but not limited to, poor self-concept, social withdrawal, problems of identity, and feelings of isolation; and (c) less likelihood of successful community integration and vocational achievement.

We do have available to us a technology of strategies and supports designed to promote social relationships among students with and without disabilities. Such strategies as cooperative learning, circle of friends, peer-mediated intervention, and direct teaching of social skills have all been demonstrated to promote successful social interactions of students with various types and degrees of disability. Further, we can also now identify some "best practices" to enhance social interaction and relationships that involve, for example, increasing opportunities for social interaction to occur; arranging social and physical environments; providing peers, educators, acquaintances, community members, and professionals with training and support to become more sensitive to interactive opportunities provided by students with disabilities; and supporting families to nurture ongoing social activities and relationships.

However, the unique challenges that persons who are deaf-blind experience in developing and maintaining meaningful, lasting social relationships continue to be virtually ignored. Most of what we know about social relationships among people who are deaf-blind comes from anecdotal reports and the literature on severe disabilities. Most of what we do in the form of intervention is incidental, circumstantial, undocumented, and extracurricular. And although social interaction skills and social relationships of students have been frequently identified as needs by parents and teachers, even with greater priority than some of the traditional areas of skill instruction, seldom are peer relationships between students who are deaf-blind and their schoolmates or neighbors targeted as instructional areas (Downing & Eichinger, 1990; Giangreco, Cloninger, Mueller, Yuan, & Ashworth, 1991).

Psychological Barriers to Social Relationships

Why do many students who are deaf-blind not have meaningful social relationships? We could argue that their integration and inclusion in general school and community programs have proceeded slowly (Fredericks & Baldwin, 1987) and that, correspondingly, we have been slow to identify and enact our new priorities in these environments. But merely increasing social opportunities will not necessarily lead to meaningful social relationships. Along with existing social and physical barriers, there remain numerous *psychological* barriers as well, and these can lead to reality gaps in our efforts to enhance social relationships even after the other barriers have long been removed.

First, our progress is delimited by fear and concern over what more integration and inclusion in the school might mean for the individual student. We fear that the uniqueness of those who are deaf-blind will be lost in more general education programs, or that more inclusion may mean less of something else—mentorship, contact with a community of peers, one-to-one instruction, or equilibrium in family life. As one parent recently put it, "Thinking about inclusion is very painful for me. I understand it and I'm all for it, and I want it for every child in Billy's class, but not for Billy." Meaningful and diverse social relationships are essential to target as psychosocial supports for students who are deaf-blind. But whether they are enhanced must not boil down to the making of painful decisions. Increasing social opportunities requires intervention and

change, which will have consequences for students, their families, educators, and peers. The critical issue is not whether we can provide opportunities for increased inclusion—we must—but whether we can openly address our fears and hopes as we move forward to ensure that there are no trade-offs or compromises in supports and services as the consequences of change.

Second, there remain many predispositions, attitudes, beliefs, and expectations about the forms and nature of social relationships that students who are deaf-blind have or can experience. Certainly, such psychological barriers exist among members of the general public, but they might also be reflected by our own concepts and interventions to provide support for the development of social relationships. When I recently visited a public school, a special education administrator pointed to a student who was deaf-blind with severe mental retardation. Knowing of my interest in socialization, he asked me, quite innocently, "You don't want to work with him, do you? What kind of social interactions can *he* have?" I was initially disturbed by his comment, not because of its apparent insensitivity, but because it forced me to think about how I and others might view the social relationships of this student. Are we content to define "social relationships" as increased contact with members of the general school population? As interactions during community outings or school functions? As acquaintances of the friends of siblings? Or is "social relationship" something deeper which we must attempt to facilitate? Our ability to make inroads into this area of need can only be as good as the way we define the essence of meaningful social relationships for the children, adolescents, and young adults who need our assistance in forming them. We have recognized the need to expand opportunities for social interaction; we must now be more vigorous in helping to extend these interactive experiences into the deeper bonds that all students have the capacity to form.

Third, the continued need to enhance social learning represents another critical issue. I do not refer to the social learning of individuals who are deaf-blind, but to that of the rest of us—professionals, peers, co-workers, and family and community members. We have tended to emphasize the teaching of communication and adaptive skills *to* students who are deaf-blind as opposed to the exchange and sharing of social experience *among* members of a community (e.g., Rowland & Stremel-Campbell, 1987). If we wish to support relationships and not merely acquaintanceships, we must begin to target in our model programs, research, and interventions not only the individual who is deaf-blind, but also the dyad or partners or groups of people with whom the individual might enjoy ongoing and long-term association. I also mention, in this respect, that we have grossly underutilized the insights, techniques, knowledge, experience, and wisdom that siblings, interpreters, teacher assistants, mentors, tutors, and home attendants might offer to the rest of us about interactions and the specialness of relationships.

What do social relationships have to do with psychosocial personal health? Meaningful, natural, and lasting social relationships are better tonics for psychosocial well-being than our more formal, prescriptive measures. Emotional or behavioral problems are negatively correlated with, or reduced by, the degree and extent of social relationships. The social health of families of persons who are deaf-blind is positively correlated with, or enhanced by, the degree and extent of social relationships. We need to recognize and invest in meaningful relationships as powerful educational and psychological

supports for children, adolescents, young adults, and their families.

Management of Undesired Behaviors

As a college freshman taking my first psychology course, I saw a film about young children who seemed to ignore other people and who engaged in headbanging. The film documented how these children were given shocks when they banged their heads and how they received rewards when they made eye contact or vocalized. In those days, we talked about "modifying behavior," and our language included such terms as "extinguishing," "shaping," "conditioning." Behavior principles were tools of science, not education.

Fortunately, years later, by the time I met my first "client" who was deaf-blind, a young woman named Addie, the philosophy, technology, and language of behavior management had evolved in very many and, generally, very productive ways. I was supposed to evaluate Addie's cognitive, adaptive, and communication skills. (Functional skills weren't to be discovered for several more years.) But Addie, who was short and very heavy, was interested in crashing her head against walls and doors. I spent our first 10 minutes together as her buffer. I was not modifying her behavior. On her own volition, however, Addie eventually discovered various learning materials that had been placed before her, and for the next full hour, she took great interest in performing tasks, not once attempting to hit her head.

Educative Approaches

Our aversive techniques have been largely replaced by approaches that seek to use a person's natural interests to motivate change. In recent years we have been consumed by humanitarian concerns over aversive treatments, which is reflected by our shift in emphasis from "modifying behavior" to providing "positive behavioral support." Beyond that, behavioral methods have been translated into educative approaches that can be applied in the home and community, as well as in the classroom (e.g., Meyer & Evans, 1989). We know that although problem behaviors may be spurred by an individual's need for reward, attention, escape, or sensation (Durand & Carr, 1985), some are also forms of communication that are as functional as conventional language. We have learned to change the forms of undesired behaviors without changing their important functions, such as communicating interest, need, or desire. For example, if a young adult lashes out at work when she becomes fatigued or overwhelmed, teaching her to use a gesture or sign to request a break can reduce the more aggressive acts. Further, still, we have recognized that behavioral techniques alone are ineffective. They must be integrated into the educational curriculum as a multicomponent package involving the training and commitment of staff, adaptation of social and physical environments, and identification of the strengths and interests of the student. We've come a long way since the days of shock sticks.

The management of problem behaviors presented by many children, adolescents, and young adults who are deaf-blind is often a psychosocial priority, particularly for those with cognitive disabilities or for whom direct behaviors—laughing, yelling, hitting, grabbing, hugging—represent a major way of communicating and interacting. The problem behaviors can range from mild and irritating actions that we can basically tolerate to those that are violent and life threatening, and which require immediate, ongoing attention. Depending on the frequency and severity of the problems, they

can be emotionally debilitating for families for periods of years.

Unique Behavioral Concerns

There are several unique aspects about behavior problems manifested by children and adolescents who are deaf-blind. First, the behaviors often start very early in life because of reduced sensory stimulation through the primary channels. The need for stimulation is a powerful human need, a craving, an innate capacity, *a survival mechanism*. Therefore, replacing or reducing behaviors which provide sensory feedback from vibration, movement, or auditory or visual patterns and variation can be very difficult. Second, the forms of behavior problems among individuals who are deaf-blind who have other multiple disabilities are often very severe and perseverative. My impression is that these severe problems are more of the self-injurious than the aggressive variety, although both occur and, many times, occur together. Third, the onset of behavior changes can be sudden and marked and can be associated with disruption of daily routines, disinterest in activities that might have been motivating and productive, or change in social and functional skill levels. Such drastic changes can occur in individuals with mild, as well as severe, cognitive impairments.

We have made great strides in our understanding of problem behaviors and how to address them. In fact, we have numerous documented reports illustrating the use of positive approaches to reduce tantrums, improve the pace of eating, eliminate enuresis, decrease head slapping, promote communication and social responses, and so on, specifically among students who are deaf-blind (e.g., Luiselli, Myles, & Littman-Quinn, 1983; Sisson, Van Hasselt, & Hersen, 1987). These truly represent impressive and important achievements, and demonstrate how tools of science and education can be utilized to make real differences in psychosocial health.

Critical Issues of Behavior Management

What, then, are the reality gaps and critical issues? There are several.

Inaccessible technology and supports. Despite the existence of state-of-the-art behavioral technology and supports, they are not available in these forms to most students who would benefit from their application. In many school settings, educators and related service providers may not have the administrative support to implement these practices. In regular schools, persons who are traditionally responsible for counseling and behavioral issues, such as guidance counselors and school psychologists, usually do not have direct experience with students who have more than mild disabilities. Consequently, most successful behavior intervention packages, certainly those that have been presented in our literature, require a considerable investment of professional or consultant support, as well as the commitment of time, money, coordination, and energy on the part of special educators, general educators, and peers in integrated settings. These resources are scarce.

Little understanding about the long-term development and evolution of problem behaviors. We view problem behaviors reactively, that is, by dealing with them once they become of concern. We know little about very early behavioral manifestations that might be benign or even appealing forms of what may later turn into problem behaviors. Consequently, we may miss early opportunities to intervene, to provide children with experience in which their natural motivations—behaviors of psychological survival—are neither modified nor managed, but *nurtured* into meaningful interactions with other persons.

Uneven support for families in which a member has problem behaviors. My list of concerns is long, so I will only highlight those shortcomings that affect our ability to make real differences. Family input is often slighted. Our behavior plans tend not to include the natural methods that families have learned that may be uniquely effective. The plans often don't apply to situations arising outside of school. Parents, care providers, and siblings may not have adequate involvement in designing intervention plans that work in school but which are also expected to be carried out at home. We tend to target the individual who has undesired behaviors, as opposed to recognizing the family as the unit of concern.

Ineffective behavioral intervention. Our current models of behavioral intervention are technologically sophisticated, but we often have difficulty accommodating them to real life. This isn't to suggest that the models are irrelevant, but that, to be more effective, we also need to learn how to do some troubleshooting when, for example, staff is inconsistent, the plan isn't adhered to, records aren't maintained, and changes don't happen the way they are supposed to. These are realities that every one of us deals with on a daily basis, but that we tend not to factor into our equations. Similarly, we tend to ignore or brush aside our failed attempts or most challenging situations. We rarely read case studies in which the behavior plan *didn't* succeed, yet analysis of our failures or difficulties can lead us to develop intervention methods that are more robust or widely applicable.

Inability to accept uncertainty. We tend to demand singular explanations, cause and effect, and clean ways of interpreting behaviors because they lead to clean intervention plans. We use checklists or bring in experts to suggest the specific reasons for a student's undesired behavior or sudden changes of behavior. Actually, sometimes we are unable to comprehend the reasons, and this can be more frightening and frustrating to us than the behavior itself. However, our inability to accept uncertainty as an explanation can create considerable gaps between the results we desire and those we achieve. It prevents us from thinking about changes of behavior more dynamically, in which (a) complex patterns of events, *as well as time*, must be dealt with instead of singular behaviors, and (b) levels and layers of support and intervention may be more appropriate than specific behavior plans.

Mental Health and Counseling

Robert Smithdas (1981) once wrote, "Psychologists and teachers working with the deaf-blind can only present objective observations that they glean and analyze from observing the behavior and reactions of their clients, but this objectivity is far from perceiving the inhibitions, frustrations, and emotional needs of the deaf-blind themselves" (p. 42). Some things can't change.

Although we can now describe some of the psychological issues, states, conflicts, and dilemmas that persons who are deaf-blind and their families are likely to deal with, as much as we might try, we can never truly live through their affective experiences. Nevertheless, there have been significant advances in the support of mental health through counseling, therapy, and general health care. Thanks, in large part, to the personal accounts of individuals who are deaf-blind, our consciousness about mental health needs has been raised; numerous first-hand resources exist to help individuals, families, and professionals anticipate stages, phases, or reactions to changes and

problems. Yet, there are numerous reality gaps in attending to psychosocial health needs of individuals and families.

Coordination of Medical and Educational Communities

A major chasm continues to exist in the coordination of health and educational services. Evidence of this comes from our own symposium, which does not specifically include representation of the medical community among the selected topics. Extraordinary improvements have been made not only in identifying infants with sensory and dual-sensory impairments, but also in keeping them alive. Positive psychosocial mental health should begin here; yet because of the walls between our medical and early intervention establishments, support services to parents—guidance, information, counseling—are often provided in fragmented, confusing, or contradictory ways. Many young parents with whom I have met are overwhelmed by their own fears and beliefs, medical findings that are unclear or are difficult to process, and the demand to consider foreign procedures, all during a time that they are just coming to grips with being parents.

Similarly, some of the emotional and behavioral concerns that arise for school aged students and young adults may be related, in part or on occasion, to medical and physical health problems, such as onset of sensory loss or changes in health or physical condition. Many physicians and health care workers do not concern themselves with the social, emotional, and educational impact of these changes. Many educators and related service providers do not consider the medical implications of changes in functional skills or mood. Conversely, many of our medical clinicians represent our best sources of experience and knowledge about social, educational, behavioral, and life-span issues, yet we tend to view them only in terms of providing for health care needs.

Psychiatric and Psychological Treatment

The incidence of major psychiatric and psychological problems and disorders among individuals who are deaf-blind is extremely high, but adequate services are difficult to come by, and they continue to be dominated by general concepts and theories of mental health. There are several critical issues here.

First, accessibility to quality and specialized services is limited and is likely to remain so. Despite our raised consciousness about psychosocial needs of individuals who are deaf-blind, the problem of obtaining adequate services is actually getting worse. However, this situation has arisen for all the right reasons. With increases in community-based residences, programs in neighborhood schools, employment opportunities in competitive settings, and integrated preschools, responsibilities for psychological, counseling, and psychiatric services have shifted to professionals working in community settings and regular schools whose experiences with persons who are deaf-blind may be minimal. On the one hand, this is an unacceptable situation, but on the other hand, those clinicians represent a natural, expanded base of human resources if they are provided adequate training and support.

Second, we lack models of psychiatric care and psychotherapy that take into consideration issues unique to people who are deaf-blind. Misdiagnoses and misinterpretations are common. A clear example of this was described 15 years ago at a conference on Usher Syndrome. In one paper (Altshuler, 1978), it was reported that 11 patients with Usher Syndrome who were admitted into a hospital's psychiatric unit over a period of several years had classic signs of schizophrenia, including

hallucinations and delusions. The author, upon reviewing the records, reported that the "psychotic episodes" in each case occurred during the final stages of loss of sight, and reclassified the presenting problems as depressive or stress reactions related to progressive visual sensory loss. Related problems arise in psychopharmacology in which medications are considered for behavioral or emotional symptoms. Misuse of medicine is directly a function of misdiagnosis of reactions or responses that may be situationally unique to the person who is deaf-blind.

Third, our forms of psychosocial service delivery to support mental health are not powerful enough to effect long-term change. Counseling and psychotherapy in schools and clinics might be strengthened and expanded by utilizing integrated team approaches, as is the case with delivery of educational and related services. This is not to suggest that a student be deprived of the special and confidential relationship he or she might have with a particular counselor or therapist, but that cross-disciplinary collaboration around psychosocial issues would enhance awareness and recognition of, and sensitivity and attention to, a student's emotional concerns. Children, adolescents, and young adults who are deaf-blind are more vulnerable than most other persons to periodic emotional instability, problems of social acceptance and integration, confusion in response to sexual desires and needs, anxiety in new environments, adjustment reactions to sensory changes, and late-onset problems. Team collaboration would be more effective in anticipating problems that can later intensify.

Family Support and Counseling

If there has been any change in the delivery of psychosocial services to individuals who are deaf-blind, it has been the increased focus on family support and counseling. Family support services, provided consistently from early on, are now recognized as essential to a student's psychosocial well-being.

Concomitantly, we have seen greater recognition of the special needs and issues of the siblings of persons who are deaf-blind. Numerous parent networks and advocacy groups, specifically dedicated to the needs of individuals who are deaf-blind, have formed in recent years. Further, the clinical orientations of therapists and counselors have increasingly shifted toward family systems theory, in which each member of the family is given equal weight, and supports and interventions are developed for the family as a unit.

However, there are a few barriers that limit the effectiveness of our efforts. The major barrier is a conceptual one regarding the professional-parent relationship. Most of our psychologically oriented training programs continue to emphasize a hierarchical parent-professional relationship in which families in therapy or counseling are viewed as dysfunctional, maladjusted, or simply helpless. This tends to set off a ritual in which "parents may suppress their fear, whereas professionals may mask their fear to maintain an illusion of expertise" (Giangreco et al., 1991, p. 22). Thus, despite our "lip service" to empower families, at least with respect to the provision of psychosocial supports such as family counseling and therapy, there is still a long way to go.

There is also a crevice, if not a full-fledged reality gap, due to *over-service*. Many families have very diverse but inconsistent sources of so-called psychosocial "support," encountering psychosocial health professionals across hospitals, clinics, preschools, schools, colleges, vocational training programs, and summer camps—more therapists per capita than Cape Cod in August. Our health care and

educational systems do little to offer parents and families integration and consistency of psychosocial support over the life span of the individual who is deaf-blind.

If nothing else, the 1992 Presidential campaign reminded us that families and households are more diverse than ever. Clearly, we are not at all prepared to provide adequate support for the psychosocial needs of nontraditional families—parents who require considerably more outreach and social services and whose issues may be very different from those of traditional families, families from various linguistic and ethnic backgrounds, and grandparents taking parental charge. Further, many children with dual sensory impairments are in foster care. A small but growing number of families in which one of the members is deaf-blind also have multiple problems which may include lack of adequate housing, insufficient child care, concerns over domestic violence, and other very difficult social conditions. Our development of psychological supports for these families is a top priority now and in the immediate future.

Future Needs, Future Directions

Our accomplishments in the delivery of psychosocial services to persons who are deaf-blind and their families have been many. Our research and knowledge base about the extent and range of psychosocial needs and specific issues in emotional development over the life span has vastly increased. Our behavioral technology and theories have advanced in both sophisticated and humanitarian ways. Against this backdrop of impressive growth, we have asked, "Are we making real differences in the lives of people who are deaf-blind?" I have suggested that there are numerous barriers that may limit our ability to make real differences, preventing us from achieving what might be possible, given the state of the art. Although these reality gaps might be construed as "dark clouds" in the delivery of psychosocial services, they are also openings to "blue skies," or the services, models, concepts, theories, and practices that we will need in the future to make a difference.

We might begin by fantasizing about formal collaboration and teamwork between medical and educational personnel as a means to reduce replication of services. This teamwork mighty also reduce insensitivity, the failure to translate findings into positive goals and objectives, inconsistency in goals and coordination of services, poor dialogue or lack of communication about behavioral or psychosocial concerns, and distrust or misperceptions about each other's opinions, roles, and responsibilities. Having spent much time thinking about how this might best be accomplished, I would propose that our federal government establish an innovative department called Health, Education, and Welfare to achieve greater unity among the professions. Short of doing that, we might wish to do the following:

1. Increase the involvement of members of our community mental health centers, clinics, hospitals, and private medical and mental health offices in our education and training endeavors, both as participants and as learners. Developing workshops or other educational forums for members of the medical professions and increasing the involvement of educators and family members in the proceedings of professional organizations represent some initial ways to promote dialogue and partnership.

2. Develop integrated models of mental health assessment and care, or positive behavioral support. Our traditional one-on-one psychotherapy, behavioral management planning, and counseling models may be insufficient to deal with the complexities of

the behavioral and socio-emotional issues that many persons who are deaf-blind face, which often reflect the interactions of environmental and social factors such as isolation, sensory status, stress and frustration, physical or bodily changes, and other conditions, some of which we may not be able to identify. An integrated model would promote the concept of team responsibility in which there is a unified service plan among counselor, therapist, job or mobility trainer, rehabilitation counselor, teacher, parent, and physician when there are concerns about behavior management and/or socio-emotional functioning.

Several inservice and pre-service training projects have attempted to expand the skills of professionals in the mental health services toward meeting needs of individuals who are deaf-blind. For example, we have had many special projects to train psychologists to provide services to students who are deaf-blind. These are important training activities, but not sufficient to make a substantial difference in the long term. There will always be shortages of qualified psychologists, social workers, psychiatrists, and counselors. Thus, we need to consider different ways to expand our services.

3. Eliminate "territoriality" of psychosocial services by offering increased support to our valuable human resources who are already interested or invested in services to persons who are deaf-blind. A cost-effective and realistic approach would be to increase the expertise of teachers, classroom assistants, job trainers, mobility specialists, and many others who may already have close relationships with, and valuable experience serving, individuals who are deaf-blind, enabling them to design and monitor behavioral programs, provide counseling, support siblings, or monitor mental health status.

4. Downplay the concept of specialist and invest money and energy toward creating better generalists among our service providers. The majority of appropriate psychosocial services available to persons who are deaf-blind and their families continue to be provided in specialized schools and clinics, and the patterns of service delivery have remained essentially unchanged over the years. Yet, today, there is much greater demand for these services across a wider range of general educational, vocational, and community milieus, which has been brought about by our efforts and mandates to increase integration and inclusion. Concurrently, the shortage of trained personnel to meet the psychosocial needs of persons who are deaf-blind has become more severe. Indeed, the very fact of increased integration has changed the nature of some critical individual and family psychosocial issues and has called for the creation of new positions, such as job trainers in supported employment programs and inclusion coordinators in schools. It is unrealistic to think that a large enough pool of would-be specialists can be identified, recruited, and trained to meet all of our service needs. It makes more sense to go on to the next step.

5. Do some strong lobbying to our higher education institutions and professional organizations to better train psychologists, social workers, counselors, psychiatrists, and therapists serving the general population to be sensitive, and intelligently attend, to the needs of persons who are deaf-blind.

During a conference earlier this year, I spotted a colleague seated at a table with two women. I approached my colleague who was concluding an interview of these parents of children who are deaf-blind. The women were getting up to leave, and my colleague introduced us. Upon finding out

that I was a psychologist, one of the women remarked, "Have I got a few words for you!" and sat down again with her new victim. As long as we are discussing needs of the future, we might as well lose our inhibitions and fantasize about increasing the parity between family members and providers of psychosocial health services. Our psychosocial, mental health training programs and workshops are far removed from the daily and life-long realities of siblings, parents, relatives, and care providers. Although professional-to-parent training programs abound, parent-to-professional workshops, seminars, institutes, material resources, and training programs to enhance the sensitivity and skills of mental health practitioners (e.g., psychologists, counselors, psychiatrists, social workers, psychiatric nurses) don't exist. Therefore, we might consider an additional step.

6. Support ongoing forums delivered by family members designed to educate medical, mental health, and social service professionals. These should do more than merely increase awareness. Many important techniques, teaching strategies, observations, hypotheses, and experiences that have been developed or that have taken place in the home have not been identified or translated for practitioners. I would promote, in particular, the involvement of family members who require much outreach and support—families that have been underserved, are overwhelmed, tend not to seek involvement, and that may have experienced years of indifferent service. Because of the existing disparities in this type of exchange, parent groups and networks will require the formal support and partnership of our professional organizations.

It should be apparent from my earlier discussion that I have emphasized meaningful social relationships as a prerequisite for positive mental health. There can be many aspects to social relationships, including companionship, peer-group identification, sexual activity, opportunities to maintain friendships across distance and time, and camaraderie at work. In addition to targeting integrated schools in our efforts, it is just as important to look outside the school.

7. Target the neighborhood, worksite, and other public domains as environments for our programs, demonstrations, and interventions. Integration and inclusion are merely symbolic if they do not extend beyond the school building and school hours. Further, the depth of social relationships is often a function of time and continuity. We need to attend to the special challenges that students who are deaf-blind have in maintaining relationships as they get older, as they leave school, or as they make transitions between programs. Finally, we need to concern ourselves with individualized mental health services such as psychotherapy, psychiatric service, and psychopharmacology.

8. Develop a clinical data base of unique issues, diagnostic concerns, and effective treatment strategies through research, clinical documentation, and compilation of medical records. This data base will promote greater dialogue among medical service providers, mental health service providers, mentors who are deaf-blind, and family members. The data exist; the data base does not. Service providers in sparse areas or in settings where other personnel are unfamiliar with people who are deaf-blind require immediate access to questions regarding behavioral and emotional concerns. Parents and experienced mental health and medical professionals need access to information from others about similar treatment cases and outcomes. I think especially about the unknown or unusual courses of behavior and development that

children and young adults with multiple complications may take. We also need this data base to help us revise our current models and concepts under which we provide psychological or mental health services.

Conclusion

In concluding this paper, I would like to think back to the young man whom I have known for eight years and consider now what we might have done differently to change his life and that of his family. It is, of course, impossible to predict the course of human development, no less so when an individual has dual sensory impairments, cognitive disability, medical concerns, and more than 30 years of cumulative experience with these conditions in a social world that has not always been respectful or accommodating. However, when I consider reality gaps that exist in the range of psychosocial supports and services we offer, what is now apparent is an absence of an "infrastructure" to address, support, link, extend, coordinate, and evaluate his medical, educational, social, vocational, and personal needs. Although he has had access to necessary services all of his life—rubella nursery school to supported employment—the needs of the person as a "whole" were often fragmented across time, and parceled out among systems of health care, education, and psychosocial support. The whole can be greater than the sum of the parts only if the parts are assembled in cohesive ways and if the connections are maintained. The integration of services, not just within an educational setting, but across institutions, service providers, time, environments, and phases of human development, is essential to ensure that we effectively close our reality gaps—those differences between the outcomes we strive to attain and those we actually achieve.

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PSYCHOSOCIAL SERVICES: REACTION

Theresa B. Smith

Abstract: In defining the population, we must recognize the vast differences between those who are cognitively impaired and those who are not. In general, mainstreaming tends to segregate rather than integrate and leads to mental health problems, of which the most important is lack of self-esteem. Encouragement and funding of retreats, camps, and conventions of the American Association of the Deaf-Blind will provide those who are deaf-blind with regular association with role models and "natural" peers. Professionals can learn much from observing those who are deaf-blind as they live and work in natural settings made possible by the establishment of deaf-blind communities that provide essential support and an environment that fosters self-determination. Finally, professionals must recognize the value of the ideas and expertise of members of the deaf-blind community. To foster this exchange of information, children who are deaf-blind must be taught American Sign Language, and interpreting training programs, taught by national experts, should be offered on an annual basis.

Introduction

My primary contact with people who are deaf-blind has been with adults who are "just deaf-blind," most of whom are deaf-blind from Usher Syndrome. There is strong anecdotal evidence that, far from being cognitively limited, people who have Usher Type I have above average intelligence. In responding to Dr. Harvey Mar's paper, I would like to make six major points.

First, it is essential to consciously and consistently make clear who it is we are talking or writing about. Specifically, we must make a distinction as to whether the person or people are significantly cognitively impaired or not.

Second, children who will become deaf-blind (e.g., those with Usher Syndrome I and II) are currently being educated without preparation for their impending deaf-blindness.

Third, when we consider the major mental health issues of children and youth who are becoming deaf-blind, direct integration, or what has been called mainstreaming, should be considered isolation and therefore not "best practice." These children, from their earliest years, should have regular association with other children who are becoming deaf-blind and with adult role models who are deaf-blind. By adolescence, they should have been introduced in a meaningful way to the adult community in the form of local groups and the national American Association of the Deaf-Blind.

The fourth is that deaf-blind communities are not segregationist in nature. Like families, communities are a foundation of strength upon which societies are built. To advocate for a deaf-blind community is not to promote segregation; it is to advocate self-determination and support.

The fifth and related point is that our understanding of deaf-blindness and, therefore, our ability to help people who are deaf-blind comes from astute participant observation and informal interactions with people who are deaf-blind in natural settings. Hence, a deaf-blind community can be a place of learning for professionals.

Finally, in planning for the future, this paper asks planners to make a frame change, to value what the deaf-blind experience has to offer us, the professionals. We should ask not only what changes we seek in systems and practice, but also what changes may be made in ourselves.

In conclusion, I make recommendations for the future. Primary among these are: (a) to focus on services concentrated at the national and regional levels as realized at the local level, with the goal being the development of a few strong local communities; and (b) to break down the barriers between adults who are deaf-blind and professionals in the field of deaf-blindness so that the focus shifts from integrating people who are deaf-blind into the non-deaf-blind world to integrating people who are non-deaf-blind into the deaf-blind community and the deaf-blind way.

The Problem of Definition

Each of us recognizes the wide spectrum of people who are deaf-blind who fall into this overly broad category. It is, in fact, so broad and inclusive as to be meaningless. It is more useful to talk about (a) American Sign Language (ASL) people who are deaf-blind, (b) English-based people who are deaf-blind, (c) people who are congenitally deaf-blind, or (d) people who are congenitally deaf-blind with mental retardation.

This four-way division, leaves us with still broad, but somewhat more meaningful, categories. Clearly these distinctions of cognitive functioning, age of onset, native/primary language, and culture are highly relevant to all the services we offer: psychosocial, educational, independent living, rehabilitation, and interpretation.

During this conference we will likely state these distinctions explicitly, largely because of the way the symposium has been structured, but it is important to be almost overly clear about these distinctions. In our daily lives, our language about people who are deaf-blind makes them obscure to us, which in turn confounds our thinking about them. An agency that deals exclusively with people who are deaf-blind describes a friend of mine as being "high functioning." I myself have never been called "high functioning." It is reminiscent of teachers of children who are deaf describing some of their students as having some "nice hearing." The presupposition in both cases, is that the faculty is impaired. How did this assumption get made? Given his intellectual gifts, there is only one possibility: he is deaf-blind. The two disabilities have become inappropriately combined in the minds of the agency staff. However, they are not the only ones to do so. Interpreters get hired to interpret for someone who is "deaf-blind" only to discover that the client is not just deaf-blind, but is developmentally disabled as well.

The effect of using this shortened label is insidious. It (the term "deaf-blind") becomes at first, a euphemism, a reduction of the problems faced and eventually, like many euphemisms, changes meaning to include the most negative connotations.

It is likewise not enough to state the population clearly at the beginning of a paper or discourse and then use the shortened term deaf-blind throughout. It is analogous to stating in an introduction that the term "he" actually refers to women and girls as well and then using only masculine pronouns throughout a text.

It becomes particularly problematic, when we use the term "deaf-blind" with people who are not insiders, who do not work daily with the same people who are deaf-blind that

we do. This is perhaps most important when we talk with people in government who help approve funding for programs. The shortened labeling we use with each other makes it hard for us and impossible for people in government to maintain these very important distinctions.

Other terms also bear elaboration or clarification. What does "integration" or "mainstreaming" mean? Who are "peers" and in what sense?

Other Issues

Children with Usher Syndrome

Our young people who have Usher Syndrome are ill prepared for the future because, currently, they are being educated as deaf or hard-of-hearing. A few educators, recognizing their future need, have made attempts to teach braille and cane technique. These educators have found the children (who at that time still have good central vision) resistant or indifferent. These children not only need to be taught skills, they also must feel validated and supported. In addition, they ought to be exposed at an early age to good role models and connections in the deaf-blind community.

Mental Heath

Harvey Mar cited Altschuler as defining many of the symptoms of people with Usher Syndrome as being depressive or showing stress-related reactions. I myself, in listening to a televised documentary on hostages taken and held by terrorists, noted the similarity between their feelings and reactions to isolation and torture to the emotions and imagery of people with Usher Syndrome. Deaf-blindness can be an incredibly isolating and dehumanizing experience. It does not have to be. Later in this paper I suggest that the formation of deaf-blind communities is the best support for people undergoing this loss.

Mental health issues for people undergoing the gradual onset of deaf-blindness from Usher Syndrome include the following:

- loss (and the grief and rage associated with it)
- identity and a changing sense of self (and feelings of grief and shame)
- adjusting to unwanted change
- freedom of mobility
- intimacy, touch and sexuality
- intimacy, friends and lovers
- sensory deprivation
- lack of intellectual stimulation
- dependency and boundaries
- power and control in/over one's life
- access to authority

I will address each of these in turn. With the exception of the issues identified with loss and change, these issues are the same for people who are born deaf-blind.

Loss. Vision and hearing are powerful tools, giving us information about and access to the world. Some of the losses inherent in progressive deaf-blindness are obvious: driving, reading print, career choices. Other, perhaps less obvious losses include loss of easy participation in group conversations, loss of the pleasure of the look or sound of one's native language in its natural form, and loss of a peer group cohort since these people are often 10 or more years behind their peers who are non-deaf-blind in starting their careers.

Identity. Questions of "Who am I? A freak, misfit, outsider?" and "Where do I belong? What constitutes my community?" are primary issues for someone becoming deaf-blind.

People with Usher Type II often find it particularly difficult to give up the image of themselves as "normal." This loss is double edged. It is actually more often the loss of a goal or a dream, rather than loss of reality. Any acceptance by the "normal majority" has been both marginal and achieved at great price. "I'm losing my cover, my ability to disappear in a crowd," one young man said. "I always worked so hard to keep up in school," said another man in despair. If the child with Usher II has been educated in an oral-only program where signing or gesturing was considered in any way bad or shameful, adjustment becomes excruciatingly painful.

While people with Usher Type I must also change identities from deaf to deaf-blind, they move from one minority identity to another. They are not giving up any status as a member of the majority. It is not so much a loss; it is a change of identity.

Adjusting to unwanted change. Changes in vision and hearing necessitate changes in strategies. With Usher the change is gradual, but persistent and continuous. This continuous need for change is sometimes very difficult, even threatening, if the person is somewhat fearful or rigid in personality. Fostering flexibility in educational (and learning) strategies should be a goal for teachers. Creative problem solving, information gathering, and critical thinking are all essential tools for these bright, young people.

Freedom of mobility. Mobility becomes an issue for children who are deaf-blind with partial vision anywhere it is dark (e.g., camping trips, the movies, night football games). Halls or stairways that are poorly lit, stairs without handrails, open cupboard doors, stray boxes or wastebaskets in the aisles make the child appear and feel clumsy, awkward, and incompetent. Poor vision also interferes with the youngsters' ability to participate in sports. Often, they are the butt of jokes and the target of harassment.

Teenagers with Usher who live in rural areas must continue to risk driving, depend on family, or simply stay at home. Youngsters who are deaf-blind who live in cities with good public transportation must deal with the constant danger of street crossings and traffic.

Mobility becomes more and more of an issue as the youngster ages and as her or his vision deteriorates. Mobility is much more subtle and complex, unfortunately, than simply using a cane. Educational programs are ill equipped to meet the specific needs of this class of children. We must also note that mobility and communication are dynamically interrelated. In order to travel widely, one must often communicate with strangers along the way. To communicate with friends, one must get to where they are.

Intimacy, touch, and sexuality. Issues of touch, intimacy and sexuality become confused. Touch eventually becomes the channel through which the person who is deaf-blind communicates, orients herself or himself to space, gets information about objects in the environment, and perceives beauty. American mainstream society sees touch as primarily sexual. Children who are deaf-blind (and children who will become deaf-blind) must be protected from taboos about touch.

Again, there is often a difference between the experience of a child raised in deaf/deaf-blind culture and one raised in an isolated, mainstreamed setting. People who

are deaf, men and women alike, use touch to communicate more than do mainstream Americans. Touch is social, not sexual. Using touch for the reception of language requires quite a leap for children raised in mainstreamed settings who have often learned to interpret all touch as intimate.

Like all social behavior, the use of touch in this way is rule governed, or culturally governed. Young people who are deaf-blind need adult role models who are deaf-blind (culture bearers) to show them how.

Intimacy, friends, and lovers. The question of intimacy itself is central to the issue of "integration." One is intimate with people who are like oneself. We are closest to people who share our generation, our major values, interests, perspectives, and experiences.

The incidence of deaf-blindness is so small as to make appropriate grouping difficult. Children who are deaf-blind need regular opportunities to learn and play with others like themselves, with true peers. Children who are deaf-blind with Usher should have summer camps, winter camps, and occasional regional intramurals just for them. These will provide opportunities to practice healthy intimacy which may result in long-lasting relationships.

Dependency, intimacy, and boundaries. How does a person who is deaf-blind interpret the world. Much of her or his access to the world, to information, is through the perceptions of others. It is no surprise that the role of Annie Sullivan and her relationship to Helen Keller was challenged. Interpreting is always an intimate affair. Interpreters act as a conduit; they are also an unconscious screen. If a person who is deaf-blind has access to only a few interpreters, no matter how faithful they try to be, the result is, in this sense, limited.

People who are deaf-blind cannot be independent in the same way they were before losing their vision. They must redefine independence, resolving the distinction between autonomy and independence.

Inability to drive and the need for interpreters, readers, and expensive equipment create extra challenges to familiar boundaries between people who are deaf-blind, their spouses, friends, interpreters, and colleagues. Who owns the problems? What assistive devices or resources are available? School programs for children who are deaf-blind should teach, accept, and encourage cooperative, independent thinking, and action.

Power and control of one's life. The issue of power and control is not separate from those of loss, identity, change, mobility, boundaries, dependency and so on. They are cumulative. Together they mount an incredible attack on the self-esteem of a person who is deaf-blind and a weakening of the resources with which to be assertive or to advocate even on a micro level for oneself.

One man of 37 who is deaf-blind, whose ability to see and understand signs was markedly influenced by proximity to the signer and lighting conditions, was frightened to ask for such accommodation. He was a college graduate, lacking neither the sophistication nor ability to articulate his needs. What he lacked was self-esteem.

Barriers to power and control include the following:

- stress on quantity rather than quality (the numbers game)
- the destructiveness of the minority experience

- the need for a critical mass
- the significance of control by other than members of one's own group
- the status, hierarchy, and rigid boundaries which currently exist between people who are deaf-blind and people who are non-deaf-blind

Granting agencies are interested in numbers. They often want to know, not only how much impact their money will have for a particular individual, but also how many people's lives will be changed. People who are deaf-blind can never compete when numbers must validate need.

The importance of deaf-blindness as a minority experience cannot be overemphasized. It is important for every child to have her or his experience and feelings validated. Children must occasionally have an opportunity to be the "unmarked case," just one among many. They need role models, examples of strategies, careers, and lives, and they must have members of their own group in positions of power. We are all familiar with the concepts of critical mass and systems versus aggregates (the whole is greater than the sum of its parts). It is virtually impossible to empower a person whose experience is unique and who must therefore solve all life's (deaf-blind) problems alone without input, stimulation, and support from peers (other people who are deaf-blind). Further, the population of children who are deaf-blind is not evenly distributed. Outside Louisiana, children with Usher Syndrome form a tiny minority within a minority. Given the history of children who are deaf-blind being lumped together as a category, their needs too often get swallowed up by the majority of children who are deaf-blind (developmentally disabled). It is useful to ask what education of children who are deaf-blind would be like if all parents, educators, and administrators were themselves deaf-blind.

Status is also a power issue. How often do professionals set out to learn from parents or to become fluent in ASL? We may attend lectures presented by adults who are deaf-blind, but do we attend or read the minutes of the American Association of the Deaf-Blind? As Dr. Mar has said, there is an implicit hierarchy. This skews our thinking and puts up unnecessary barriers to our own (professional) learning.

Access to authority. A related power issue is access to the ear of those in authority. People who are developmentally disabled deaf-blind are represented by their parents. People who are just deaf-blind speak for themselves. This is appropriate, but, in practice, not entirely fair.

I am sure that parents often feel frustrated in their attempts to make their needs and vision clear to those in power. They undoubtedly also feel the strain on their resources of time and energy spent seeking appropriate services with only minimal success. Yet their children are better represented than are people who are "just deaf-blind" who must also deal directly and daily with the barriers imposed by deaf-blindness.

People with Usher Type II, like the parents just mentioned, have English as their first language. Yet, they cannot simply look up the names of lawmakers and their voting records, hop in a car to attend a meeting, or read the newsletters of other organizations or groups who may be supportive to their cause. Before they even begin, they must obtain and learn to use Teletype Devices for the Deaf (TDDs or TTYs), learn to read braille, and learn how to use interpreters. Even these provide limited access. Conversations by TTY's take much longer. Not much is available in braille. Who will pay for the interpreters? When information

is finally gathered, agenda set, and meetings are called, how will a person who is deaf-blind get transportation to attend?

People with Usher Type I have language and cultural differences separating them from those in positions of power. Typically for them, English is a second language. All the confounding factors of cross-cultural communication apply. Communication through interpreters is at best tedious.

It is extremely difficult to find skilled and appropriate interpreters for people who are ASL deaf-blind. Mere interpreting is an incredibly challenging task, calling for intelligence, skill, knowledge, sensitivity, years of training, and experience. Paradoxically, interpreters in schools are paid very low wages and are typically given the status of an "aide." Interpreting for people who are deaf-blind requires additional skills, knowledge, and sensitivity. Interpreting for professionals who are deaf-blind requires all of the above plus a minimal level of expertise in the subject being discussed.

How then can people with Usher Type I approach people in positions of authority? Requests for proposals are in neither a language nor a form that is accessible to them. Their own presentations in ASL, made through interpreters in symposia such as this, often appear odd, quixotic, or as one listener said "full of information, but lacking a point." ASL is a different language having not only a different lexicon and syntax (vocabulary and grammar) but a different discourse style. The modalities do not match. The answer is not to try one more time to teach them English; it is to provide access to information and appropriate interpreters.

All of this can be overwhelming.

Integration

Dr. Mar's paper repeatedly raises the question that we must all ask ourselves. In effect, he asks if what we have been doing actually makes the lives of people who are deaf-blind better. This question is central! I would suggest that our emphasis on furthering integration is actually a disservice to this population. The question is not whether we are going about integration in the best way. The question is whether or not to go about integration at all.

Access gives power. When adults who are deaf and deaf-blind discuss integration, they do not say they want to socialize with hearing people. They never ask to be scattered, divided, or separated from their peers who are deaf or deaf-blind. They do say they want to have access to jobs, information, education, and entertainment. Hence people who are deaf and deaf-blind do not ask for mainstreamed programs for children (the most vulnerable). They do lobby for input at a decision-making level, for TTY distribution programs, TTY relay services, and closed-captioned television programs and videos.

At all the conventions, symposia, and meetings I have attended I have rarely seen hearing professionals regularly seek out the company of adults who are deaf-blind. If they do so, it is cordial, but brief. It is done purposefully, intentionally, not naturally, or casually. While hearing professionals associate with adults who are deaf-blind, they do not socialize with them as real peers or friends. This despite the fact that these same people who are deaf-blind, like the hearing professionals, have advanced degrees, interesting jobs, children, common hobbies, and so on.

I am not berating hearing professionals. I believe this separateness is normal, which, in fact, supports my point that integration is not

the answer. There is a basic, fundamental difference between the experience of being deaf-blind and that of being non-deaf-blind. There is a resultant profound difference between people who are deaf-blind and people who are non-deaf-blind.

If this lack of real integration is true for professionals who spend a significant amount of their time working with people who are deaf-blind, how much more is this true of classmates, regular classroom teachers, neighbors, co-workers, and so on? In what sense do we mean that children who are developmentally disabled and deaf-blind should be integrated with their "peers"? In what sense are they peers?

While people who are non-deaf-blind can be part of the support network for people who are deaf-blind, we can never be enough. The need for real peers (a community) begins early. Toddlers recognize other infants in the grocery store from their strollers, point to them, and want to play. Parallel play is an early form of peer interaction. Children who are deaf-blind also need the experience of community (with other children who are deaf-blind), information about the adult community, and direct access to this community as they approach adulthood.

The Deaf-Blind Community

Years ago, when I first started interpreting, I met a woman, an aunt of three children who are deaf who asked me what it was an interpreter did. I explained my job, using examples of doctor visits and so on. The woman said (somewhat testily), "Well, wouldn't it be better if they could just talk to the doctor themselves?" Obviously, this was in the days of oralism, and frankly I was both astonished and exasperated at her inability to notice that her three teenaged nephews and niece, despite years of arduous training and dedicated, responsible, active parents, still could not talk in a way that was intelligible to anyone outside the family.

The answer I wanted to give was, "No, it would be better if all the doctors could sign." This would have been no more realistic, but it would have enlightened her own position. It would have shown it to be wishful thinking, and worse, wishful thinking from the position of the majority of which she is a member, not from the position of her niece and nephews.

She was not a stupid woman. She was not uncaring. She just got stuck in her dream of having a niece and nephews who were not deaf, who were like her, who were "hearing," and so she could not get beyond this to ask herself what the dream of children who are deaf might be, what might be wonderful for them if they were not ever going to be like her. She didn't let herself take a different perspective.

A deaf-blind community, on the other hand, offers a tool for true integration. It provides a model for living in the world, a range of sample strategies, a culture. It offers validation of the deaf-blind experience. It provides intimacy in the form of true peers and a critical mass from which to seek friends and partners. It offers the major vehicle for access. Any community, including a deaf-blind community may be said to offer the following benefits:

- language and culture
- peers and social relationships
- intimacy
- appropriate challenge
- a continuum of roles to fill
- shared resources
- the power of collective action

- the possibility of political action
- the channel for access to the wider society

Social relationships. Harvey Mar mentioned the importance of social relationships, and this was a major part of his paper. Social relationships require skills—social skills. As we have seen, children who are deaf-blind in a group of hearing-sighted children do not get any opportunity to be truly social.

Social skills are not equivalent to manners; they are not learned (or effectively taught) formally. They are developed naturally at home, in the neighborhood, and on the playground from regular interactions with others.

A few years ago I went to a carnival where I ran into a youngster with Usher whom I knew. I chatted with him and tried to introduce him to an adult person with Usher who was with me. The youngster had no good sense of turn taking or an appropriate flow of conversation topics. He interrupted me repeatedly and I was unable to ever make the introduction. Finally, when he just turned and ran off, the adult I was with said with a sigh, "Mainstreaming!" He was right. The youngster has caring parents who sign well and devote many hours to him. His teacher is likewise devoted and skilled. But his siblings are all hearing, he was being schooled in a small town mainstream program, having few other children who are deaf and no other children with Usher. When I met his teacher a few months later, I mentioned my concern about this child's social skills. The teacher responded that the boy had excellent social skills, but perhaps didn't know how to be a friend. What the child actually knows, of course, is how and when to say "please" and "thank you" and "excuse me." He has excellent manners.

Mainstreaming gives children who are deaf and deaf-blind a sense of themselves as special, as freaks, as slow, clumsy, and incompetent. If they are also discounted on other characteristics such as being female, or African-American, they have little chance of developing a positive self-image. I am speaking here of children with average or better-than-average intelligence.

Analogies between mainstreaming and oralism are obvious. The parallel is instructive. The attempt was and is to "normalize" children who are deaf and deaf-blind. The assumptions are the same:

- Power comes from accommodating (fitting into) the majority.
- Decisions should be based on considerations that include the advice of people who are deaf and deaf-blind, but should be made by members of the majority (hearing-sighted people).

The irony is that when oralism or mainstreaming are the goal, people who are deaf and deaf-blind are more isolated than ever, but when signing is accepted and when ASL and the community are appreciated, when appropriate interpreters are hired and people who are deaf are consulted as a group, people who are deaf for the first time will be able to access the larger society. This appreciation comes at three levels:

1. At the level of modality
   - oral speech is not viable for children who are deaf (hearing modalities don't work for children who are deaf/deaf-blind).
   - mainstreaming does not work.
2. At the level of world view
   - people who are deaf/deaf-blind really do know more about deaf/deaf-blind

education and appropriate methods than (even highly educated, highly intelligent) people who are non-deaf/deaf-blind.

3. At the level of the implications

   - people who are deaf/deaf-blind should have control (not merely input) of the decisions regarding the systems of education of children who are deaf/deaf-blind.

In the education of children who are deaf-blind, we have barely achieved the first level.

Appropriate challenge. Thinking skills are very much a part of both social relations and of good mental health. Certainly these are developed primarily in interaction with one's peers. This is true for people who are developmentally disabled as well as for those who are not. Two weeks ago, I had a 45-minute conversation with a young woman who is developmentally disabled deaf-blind whom I had met four or five years ago. When I first met her, she had just graduated from school and started work at the Seattle Lighthouse for the Blind. At that time she was fearful of much physical contact (i.e., hugs) and could not in any sense carry on a conversation. Interaction with her consisted exclusively of her asking everyone their birthday. In five short years she has learned to carry on a relatively normal introductory level conversation (as I said, she held my interest for 45 minutes). She has even learned to spontaneously relate her experience with a llama in a very poetic and moving way to a group of people who are deaf-blind at a campfire storytelling session.

This woman is not a single, exceptional example. There are at least seven other people (all who are developmentally disabled/deaf-blind) in the Seattle community who have responded to the community experience in the same way.

People who are congenitally deaf-blind who either are not cognitively impaired or are minimally so, can blossom in a deaf-blind community. Ready access to appropriate language and culture stretch their abilities while giving them role models and "visible" goals.

Thinking and social skills overlap in an ability to form an opinion, to perceive and understand the perspectives of others, to consider each perspective in light of the others, and to recognize (at least partially) the implications of the sum. Skill in this kind of thinking presupposes experience in a community, a community in which one encounters varying perspectives, their implications, and an opportunity to see them played out.

Yet there is powerful resistance to the idea of children who are deaf-blind being together. In talking with a school administrator about reducing isolation by sponsoring annual, regional camps for children with Usher Syndrome, I was told it would be seen as segregation, or separatism. How is such gathering together of children with Usher significantly different from the need for parents to talk with one another and share strategies? How is it different from the networking or collaboration we professionals engage in and promote so avidly? We must question the roots of our resistance to this obvious need.

Roles to fill. When a person who is deaf-blind is the only one in a group, she or he fills the role of "person who is deaf-blind." Where there is a group of persons who are deaf-blind, there are opportunities to fill other roles (e.g., chairperson of the recreation committee, strong arm that moves the tables) and to have an identity outside the deaf-blindness.

Pooling resources. A community pools resources and distributes the work. Seattle

has a relatively strong deaf-blind community. We could use another couple of hundred people who are deaf-blind, but we have a good start. People who are deaf-blind who are new to Seattle, definitely make use of the excellent services offered by the Deaf-Blind Service Center, the Lighthouse for the Blind, and the regional Helen Keller office, but they also have available a wealth of information, support, and fun in their peers.

Such a community encompasses a life before and beyond school, work, and agencies. It envelops life at home and weekend events. It supplies friends with whom to have a barbecue, go salmon fishing, discuss the news, and go out to dinner. One of the most important gifts of a deaf-blind community is a deaf-blind sense of humor. A sense of humor is cultural. It depends on one's perspective. Predictably, a deaf-blind sense of humor is different from a non-deaf-blind sense of humor.

Collective action. One task of childhood is learning the rules, not only what they are, but who makes them and how to change them. Often, changing rules requires collective action. Transportation problems, for example, become group problems to be solved collectively, with the resource of all those brains and the bargaining power of many metro transit consumers. Out of community comes a collective voice, collective action, collective power. The need for collective action in politics is clear. The establishment of a card system or bus kit to improve the metro transit bus service to passengers who are deaf-blind resulted directly from such collective action on the part of the deaf-blind community.

Three people comprise a group, not a community. Anthropologist Marvin Harris has identified the optimal number for a community (or tribe) as about 100 adults. Significantly fewer than this do not provide enough choices for friends or enough hands to do the work.

Access. Access is dynamic. To communicate, I need to be where people are, I need experiences to communicate about. To be truly mobile, I must have some idea of interesting places to go and how to get to them. I need background with which to appreciate the excursions. I need money to spend and a job for earning it. These experiences in turn add to my communication repertoire. Education, communication, the use of technology such as computers, mobility skills, and general information about what is out there that might be of interest are all inseparable. To be an active, involved member of my community, I need access to them all.

If trying to put individual people who are deaf-blind into normal society is like trying to put square pegs into round holes, then what we need is an adapter. The deaf-blind community is such an adapter. The Seattle model is instructive. Here is a community which is unique. Essential to a model community is a certain philosophy or attitude:

- It is assumed that people who are deaf-blind always know and care more about how best to be and serve people who are deaf-blind than do professionals or parents who are non-deaf-blind. The expression of this is a collaborative effort.
- Design, planning, and growth occur from the ground up, not the top down.
- High quality communication and a sense of community are assumed to be fundamental factors.
- The usual boundaries (barriers) between professionals and clients are obliterated

and professionals are encouraged to get close to people who are deaf-blind.

- The social involvement of interpreters, instructors in interpreter training, and other professionals in the community occurs on a volunteer basis.
- There is availability of substantial, gainful employment at the local Lighthouse for the Blind with promotional opportunities and support services in the form of on-staff interpreters, teletype devices, and vibrating pagers.
- There is availability of instruction in O&M (orientation and mobility), braille, use of braille TTYs, and cooking, all in the native/primary language of the person who is deaf-blind.
- There is relatively good public transportation service (bus/van system).
- There are paid services from SSPs (support service providers) who are referred through the local Deaf-Blind Service Center.
- There are opportunities for advocacy on both the individual and system level from the local Deaf-Blind Service Center.
- There is an emphasis on quality and accountability, a willingness to challenge, be challenged, and to change.
- There is resultant mutual trust, cooperation, and collaboration among these individuals and groups (individual people who are deaf-blind, the deaf-blind community, interpreters and other professionals, agencies, sheltered workshops, the Division of Vocational Rehabilitation, and the group home for people who are developmentally disabled/deaf-blind).

Unanswered Questions

We do not know what percentage of and who, among children who are congenitally deaf-blind, are actually cognitively impaired. How many of these children would blossom in unprecedented ways when educated in a deaf-blind environment or communicated with in the way adults who are deaf-blind communicate with each other?

We do not know how much healthier (mentally and emotionally) children with Usher II would be if they were educated in bilingual/bicultural programs.

We do not know what advice adults who are deaf-blind would have for us if they were given real and regular access to education programs for children like themselves and if they were part of the decision-making processes in those programs.

The Future

More Local Communities

People who are deaf-blind need communities of 100 or more across the nation so they can choose friends and spouses and have real peers. Clusters of agencies, programs, and services should be established throughout the country in likely cities—cities already having a pool of interpreters, interpreter training programs, and good public transportation systems.

Further, they should be self-selected by people who are deaf-blind. As people who are deaf-blind begin to form natural, smaller communities (such as those in Los Angeles, Denver, Minneapolis, Pittsburgh, Lafayette), federal direction and financial support should be given in the form of grants to existing institutions so that they can begin to serve people who are deaf-blind from throughout an entire region.

Programs and services should address a wide range of issues beginning with the most fundamental: support service providers, interpreter training and referral, recreation programs, counseling, and advocacy. As these are developed, people who are deaf-blind will undoubtedly begin seeking other services: independent living skills training, postsecondary education and vocational training, employment, job development, and placement. Providing such complex, comprehensive services in centralized locations makes so much more sense than trying to have it all available everywhere.

The most effective way to get input from adults who are deaf-blind and the deaf-blind community for community services and programs is to hold regular (quarterly) "community meetings" with high quality interpreting service provided.

- People who are deaf-blind will give each other support and ideas.
- Communication needs will be honored and great care will be given to the selection and matching of interpreters. The process will match the modalities.
- Only people who are deaf-blind will be invited to participate in such meetings.
- Proceedings and results or recommendations coming out of such meetings will be recorded in any grant applications for further funding of programs.

Less Professional Distance

"Maintaining a professional distance" sometimes establishes overly rigid boundaries and prevents the best kinds of learning available to professionals. Perhaps it is a protection of our own ideas and position. Teachers, as well as other professionals, should be encouraged to participate in local adult deaf-blind communities as a regular part of their work and should attend the American Association of the Deaf-Blind annual conventions, community or group meetings, and summer camps as SSPs (support service providers) or observers. This attendance should be regular. One cannot learn it all in one experience and certainly not in a few days.

Support for the American Association of the Deaf-Blind

The American Association of the Deaf-Blind is one of the most effective and important means of increasing information flow and reducing the isolation inherent in the disability of deaf-blindness. For people who do not live where there is a viable local community, it is the single best means of addressing the many psychosocial issues facing a person who is deaf-blind. Mitigating the isolation can soften many of the stresses incurred by people who are "just deaf-blind." Offering a context in which deaf-blindness is normal and comfortable and in which behaviors (i.e., the culture, including language, manners, expectations for social interactions, etc.) are driven by deaf-blindness releases people who are deaf-blind in a way formal agencies and services cannot.

Annual conventions are held at great expense to people who are deaf-blind themselves. Each year the American Association of the Deaf-Blind spends tens of thousands of dollars simply to house and feed the interpreters and support service providers it needs. Currently, the almost 200 volunteers are about one-third the number needed, and this number jeopardizes the budget of the American Association of the Deaf-Blind.

State and federal money should support this already existing, nationally based support system. Additional money to the American

Association of the Deaf-Blind allowing the association to house more volunteers and to pay the travel expenses of qualified volunteers would greatly relieve both the volunteers (who must often work to the point of exhaustion) and the organization. In-kind donations in the form of interpreter hours should more than justify such a grant. By awarding money each year to the American Association of the Deaf-Blind, the government would greatly enhance its ability to support members who are deaf-blind, young and old.

More Camps and Retreats

Like the conventions of the American Association of the Deaf-Blind, these smaller, regional gatherings are important means of increasing information flow and reducing the isolation of deaf-blindness. They too use volunteers and offer professionals an excellent opportunity to learn. They also offer financial support for low-income people who are deaf-blind.

Regional gatherings are essential for children with Usher who are isolated from their peers without even the limited means of their elders to get together. Gallaudet's summer learning vacation offers an excellent model for this. These experiences should be made available for every child and family.

Deaf-blindness should be incorporated into the regular curriculum for all children who are deaf and blind so that they are aware of the Janice Adamses, Art Roehrigs, Janie Neals, and Harry Andersons in this world. These heros and heroines should become a part of their heritage.

Critical thinking, creative problem solving, information gathering, and so on should be a central part of the education of every youngster with Usher or other such progressive loss. Perhaps activities in camps and retreats can help teach these essential skills.

Better Communication Training

ASL should be considered as important for children who are deaf-blind as is English. The modality of sign should be paramount regardless of whether or not the children retain (and appropriately use) residual hearing.

Better Interpreter Training

No programs for youth and adults who are deaf-blind are possible without high quality interpreters. These skilled specialists virtually do not exist. Training courses should be offered in regular interpreter training programs, but beyond this, special courses, analogous to six-week, all-day courses in "legal interpreting," taught by national experts, should be offered on a national basis annually (preferably just prior to and in conjunction with the American Association of the Deaf-Blind conventions).

Summary

In this paper, I have addressed six major points. First, I have discussed problems that arise from our attempts to define the population. We must beware of generalizations and must recognize the vast differences between those who are cognitively impaired and those who are not. Second, I have pointed out that children with Usher Syndrome are currently being educated without adequate preparation for their impending hearing and vision loss.

Third, when considering the mental health issues of children and youth who are deaf-blind, I have maintained that mainstreaming should not be considered "best practice." Fourth, I have suggested that deaf-blind

communities are beneficial and are not segregationist in nature.

My fifth point suggests that we can learn much from observing those who are deaf-blind as they live and work in natural settings that are made possible by the establishment of deaf-blind communities. And finally, in a related point, I have suggested that we look at the experience of people who are deaf-blind for what it can offer us. Rather than maintaining professional distance and rigidity, we can endeavor to be more receptive to the ideas and expertise of members of the deaf-blind community.

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COMMUNICATION: PRESENTATION

Robert Stillman

Abstract: Historical background is presented as well as an overview of current programs for those who are deaf-blind. We need agreement on the meaning of commonly used terms, and we need to know more about factors affecting the acquisition of communication skills. Third, we need to learn more about these students to account for learning differences not readily explained by the presence of impaired vision and hearing, that is, knowledge of the cognitive strategies these students employ. We need better preparation of educators who now know little about acquisition of communication skills and even less about students who are deaf-blind. Finally, professionals need to reshape their thinking and techniques since most of these students are now in integrated settings. The goal is effective communication that will result in greater inclusion in society.

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Communication is the process of exchanging information. It is the way we share our knowledge, needs, wishes, and feelings. For most of us, communication is effortless. We speak, gesture, and sign, and we assume that those with whom we communicate will understand. And, usually with little difficulty, we understand what others communicate to us. Communication may seem routine. However, producing sounds and movements meaningful to others and making sense of the sounds and movements others produce is no easy task. We may not remember it, but, all of us went through extensive preparation at home, at school, and with our peers to acquire the communicative skills we have today.

Communication and language require a sophisticated array of cognitive skills and biological structures. Their acquisition is not one of stacking blocks until a tower is built. Rather, it is an interlacing of continually changing cognitive, perceptual, and memory skills; maturing neural and motor structures; and the experience of active, passive, and reactive engagement with objects and others. As a result, the emergence of communication and language has an underlying pattern common to all persons, but its features are individually unique. When we look at the myriad of factors contributing to communication and language skills, we should not be surprised that it is affected by a variety of organic impairments. However, we should be amazed that it is so resilient. Against this background, I will describe some of what we know and some of what we don't know about communicative skills and their acquisition in individuals who are deaf-blind.

Deaf-blindness is a descriptive category. It is not a category arrived at psychometrically or based on etiology. Individual differences in degree of sensory impairment, age at onset, and the presence and extent of other disabling conditions are enormous. Furthermore, environmental factors including, but not limited to, early and consistent family support systems, the availability of health services and prosthetic and assistive devices, and the calibre of educational programs further expand differences between individuals. In fact, it is not even realistic to consider oneself a specialist without specifying a particular subset of persons who are deaf-blind. For

example, my experience has been almost exclusively with students having disabilities in addition to impaired vision and hearing. These almost invariably include cognitive, motoric, and emotional disabilities, the combination of which seems to multiply rather than add to the effects of dual sensory impairments. Furthermore, nearly all of these students became deaf-blind prelingually, that is before the time they might have been expected to become language users. My interest and expertise thus reside largely in nonlinguistic and, for the most part, nonsymbolic forms of communication and in the growing numbers of students who also have severe cognitive, motor, and health problems.

This will be neither an extensive literature review nor a summary of the various devices, assessment procedures, or programs currently in use. Instead, it is a discussion of ideas regarding communication honed from our work with students who are deaf-blind and which now infuse our intervention programs. I will speak from the perspective of having done observational research on intervention with individual students rather than on the broader issues of public policy, systems change, and service delivery models.

Historical Background

To begin, a little history is worthwhile. The growth of knowledge regarding how students who are deaf-blind acquire communicative abilities and what techniques are most effective has been far from linear. It is a tangled history of rapid, abrupt, and sometimes cyclical changes; of fads and flops; and of successes and failures substantiated by testimonials. To a significant extent, the particular approach holding sway depended a lot on the region of the country, the inclusiveness or exclusiveness of the criteria used to identify those who are deaf-blind, and the auspices under which services were offered.

At least five models or approaches to communication intervention have vied for domination over the past 25 years. Each has contributed and each, in a sense, has impeded progress either through misapplication or dogmatic approaches which failed to appreciate the uniqueness among students who are deaf-blind and between these students and others with sensory or other disabilities.

Of the approaches, only one had its origin exclusively in work with persons who are deaf-blind: the movement program developed in Holland by van Dijk. The other approaches were efforts to adapt techniques used successfully with persons having other disabilities. These include behavioral approaches used with students having severe cognitive disabilities or autism, techniques derived from programs for students having deafness or blindness, and from speech-language pathology and special education in general. Thus, we have taught or tried to teach sign language, gestures, tactile signs, and object symbols. We have systematically and sometimes unsystematically rewarded random and purposeful behaviors and even punished expressions not to our liking. We have tried to emulate normal development and applied the highest levels of existing technology. Not an item on this list hasn't worked for some student and failed with another. It's no wonder that the favorite approach among teachers is eclectic.

It is also important to view our conceptions about communication, not only with regard to programs for students who are deaf-blind, but also in the larger context of the research base in child language. During the time programs for students who are deaf-blind have been established, major and rapid changes occurred. Behaviorist explanations

for language acquisition proposed by the Skinnerians were challenged by the Chomskyites who proposed that experience is merely a trigger for neurological mechanisms which organize and direct language acquisition during a critical period. The Chomskyites, in turn, were challenged by Bruner and others who saw the precursors to language not only in a neurologically based "Language Acquisition Device," but in the preverbal behaviors of infants in interactions with their mothers. At the same time, special education and speech-language pathology were discovering Piaget and his conception of the importance of the child in the acquisition of his or her own skills. The field became intrigued by the cognitive domains Piaget described and the possibility that teaching nonlinguistic cognitive skills might speed up language acquisition. There was also strong interest in sensory integration theory (Ayres, 1972) with its premise that motor and sensory losses contributed to cognitive and communicative problems and that enhancing skills in these areas might improve cognitive and communicative competence. Finally, developmental psycholinguists redefined pragmatics to encompass preverbal communications and introduced the field to the concepts of communicative functions, communicative intentions, and intentional communication (e.g., Bates, 1976), and developmental psychologists became less focused on the principles of learning than the context of learning. Their detailed descriptions of mother-infant interaction, particularly its temporal features, led to introduction of the concepts of reciprocity, turn-taking, engagement, responsiveness, and joint attention (e.g., Kaye, 1982; Lock, 1978; Schaffer, 1977). The microanalytic videotape coding techniques they employed have revolutionized how we observe interactions and collect data.

Current Programs in Communication

Against this backdrop began the work of determining how to help students who are deaf-blind acquire communication skills. In other words, not only were we faced with developing programs for students whose disabilities had previously resulted in denial of services or institutionalization rather than entry into the educational system, but the field itself was in flux. What emerged is rather remarkable and a tribute to the professionals who have contributed to the education of students who are deaf-blind.

Rowland and Stremel-Campbell (1987) described communication as a shared process. They pointed out that if communication between two people is to succeed, they must first share an understanding of the forms or acts which serve a communicative function and the way these acts are ordered and merged with the context to convey meaning. Second, they must share a common topic or focus of attention. Third, they must share an understanding of the intention underlying each other's expressions. Fourth, they must share a knowledge of the patterns and rules of discourse or conversation. But, sharing in any of these areas cannot be assumed. Often, it must be achieved.

Achieving a shared communication system requires the establishment of communicative conventions. The conventions may be between a few people, a group of people, or an entire culture. Most of what we can say about the status of communication intervention relates to efforts to establish conventions at each of these levels. We may also view these levels hierarchically since, as individuals acquire communicative abilities, they find them most effective with a few, then a group, then many people.

Let me begin with what I see as our major achievements at the level of establishing

conventions between a few people. A perplexing problem has been to establish a system of communication when one partner is a sophisticated language user and the other evidences no obvious ability to communicate at all. This is a two-part issue: how to assist students to use actions to affect others and how to assist adults to communicate in ways students understand.

The importance of identifying, interpreting, and responding to the nonverbal behaviors of students who are at the initial stages of acquiring communication is well understood. The work of van Dijk (1966, 1967), Siegel-Causey (1987, 1989), Downing (1988), ourselves (1984, 1989), and others has provided the rationale, if not always hard data, to support sensitivity and responsiveness as significant factors in assisting students to acquire communicative skills. The key is the assumption that any behavior can have a communicative function. It is the recipient who carefully observes behaviors and the contexts in which they occur and, when appropriate, gives the behaviors meaning through consistent responses. It is no longer viewed as essential to begin by teaching a symbol system or to wait until the student has achieved a certain level of motor, cognitive, or social abilities before we introduce communication. The student is allowed to capture the contingent and contextual relationships between behavior and response through the sensitivity, responsiveness, repetition, and consistency of the partner. This is not to say, however, that we have all of the answers. Disagreement remains regarding how selective to be in responding and how to distinguish potentially volitional behaviors from those which are purely reactive.

Purposefulness or intentionality is a key issue. Any behavior can serve a communicative function even if not intentionally displayed. Crying or grimacing in reaction to discomfort, smiling or laughing in reaction to pleasurable sensations, tensing or relaxing in reaction to movement, touch, sounds, or visual displays all communicate to the observer something about the student's state, interest, and readiness to interact. Furthermore, in the case of positive and negative affective displays, the expressions are socially appropriate and so possess an air of conventionality, as well. However, without volitional control, these behaviors cannot be purposely used to affect others and achieve goals. They serve an indexing, but not a communicative, function.

This issue is important because many teachers have not been trained to understand the process of communication acquisition (especially its progressive nature). The result is that they spend considerable time nurturing affective displays which do not contribute substantively to the student's overall development of communicative skills.

We have found that movements are a more viable way of establishing an initial and expandable communication system. A movement-based communication system affords students opportunities to affect others and the environment, to make choices, and to terminate interactions in acceptable, if not conventional, ways. Significant progress has been made developing signalling behaviors even among students whose disabilities are the most severe. Movements over which the student has control are paired with responses appropriate to the movement (e.g., leaning leads to rocking; hand pulling leads to the spoon coming closer; pushing away leads to a temporary cessation of the interaction). The relationship between a movement and a natural effect sets the foundation for the student to intentionally use particular movements to bring about particular effects and allows others to interpret the movements as signals indicating the student's goal.

These movements are not just reactions to stimuli. They are communicative signals shaped by the adult in the context of interactions.

This may sound like behavior modification. But, it differs in important respects. First, there is no arbitrary extrinsic reward or punishment used to reinforce the behavior. The behavior, as with all true communications, brings about a natural consequence. Second, the approach is student centered. Although assistance may be required for students having severe motor impairments, there is no effort to manipulate or force students to perform particular behaviors corresponding either to teacher-generated or conventional systems of signals, or to require students to perform for outcomes unrelated to their interests. Third, the goal is not performing to a criterion. It matters not at all if the student signals on 8 out of 10 opportunities. Perhaps the student is just not interested on a given day. The goal is anticipation. Anticipation is a cognitive skill manifested by behaviors such as signalling which indicate the student has grasped a rule. It means that the teacher has sufficiently organized the student's experiences so they become rule governed. The student expects that in a certain context, as a result of a particular action, or as a result of someone else's action, something specific will occur. Not only does this encourage the use of actions or signals to affect others, but the student can now make assumptions about what is likely to happen under certain conditions and can move on to learn new things. Perhaps most important, it engenders a sense of trust between teacher and student based on mutual expectations and few surprises. This makes the student's world much less random, confusing, and threatening. An approach which enhances the student's ability to act with the anticipation of particular results is important when one considers that the presence of visual and auditory impairments complicates the process of understanding interpersonal and environmental consistencies.

One may also embed signalling within what may be called a protoconversational context. The teacher moves with the student in a movement familiar to the student (e.g. moving the spoon toward the mouth). This may be translated as a request from the teacher to participate. The student's participation in the movement is a response to the teacher's request. The teacher then pauses in the movement. This pause alerts the student that something has happened. It is the teacher's way of asking the student whether to continue. If the student re-initiates the movement during the pause, the teacher may interpret the movement as a signal to continue. The teacher then responds to the student's communication by re-starting. This is a nonverbal dialogue. Both participants make requests and respond to the requests of their partner. The conversation is embedded in move-pause-move sequences which can be incorporated into any activity. This one simple format includes expressive and receptive communication, signalling, opportunities for choice, turn-taking, and joint action toward a goal. Furthermore, it is conventionalized between the two partners because both use the same form of communication, movement.

Although this approach has sound theoretical and empirical underpinnings, it is sometimes erroneously applied. Interactions which may be typified as "shake-and-wait" where the teacher vigorously stimulates the student, pauses waiting for a response, then restarts the stimulation involve minimal active participation by the student and, at best, afford the student an opportunity to repeatedly practice an already known signal.

At this point, those of you who are most familiar with communication as a shared

system of symbols readily identified and distinguished from other behaviors may be puzzled. However, communication in its early stages is not a separate domain. It is a relatively undifferentiated complex of affect and skills. Thus, any one behavior could be called a communication, a social behavior, or a goal-oriented movement.

Certainly, there is much more to say about establishing the foundation for communicative interactions. But, what do we know about students who have a basic repertoire of communicative signals?

Much of our progress has been made in the use of gestural or object/picture systems as described by van Dijk and more recently, the tangible symbol systems of Rowland and Schweigert (1989a, 1989b). Communication becomes conventional when users agree that certain acts, objects, or vocalizations stand for or represent something. Werner and Kaplan (1963) proposed that the ability to represent proceeded along clearly defined paths termed denaturalization and decontextualization. These two concepts have served as guideposts in our efforts to develop gestural and object-based communication systems. Denaturalization refers both in expression and comprehension for the decreasing need for similarity between the communicative act and that which it represents. The continuum ranges from using and understanding only expressions in which the communication and its meaning are the same (e.g., the teacher manipulates the student's hand to pick up a spoon in order to request that the student participate in picking up a spoon, or the student puts the teacher's hand on an object to have it activated), to gesturally demonstrating to pick up a spoon or gesturing to activate the object, to the most denaturalized or abstract communication, saying or signing to the student to pick up the spoon or signing to the teacher to activate the object.

Decontextualization refers to the ability to use and understand communicative expressions outside the contexts in which they were learned or typically used. There are two aspects of decontextualization, a spatial and a temporal component. The spatial component refers to the degree to which elements of the context define the meaning of a communication. We all use context to support our communications and to clarify the communications of others. However, for many students, the context and the communication are one. The communicative act appears to lose its meaning outside its usual context or in the absence of some aspect of the context especially salient to the student. Decontextualization is the process through which the meaning of the communicative act becomes constant regardless of where it appears and who uses it. This sounds like generalization. But, by conceiving of the failure to generalize not as a failure in learning or stimulus control, but as an indicator of the student's current abilities along the continuum of decontextualization, we can adjust the activities so they demand less decontextualization rather than focusing on further training and generalization probes.

Temporal decontextualization describes the ability to use and understand communications referring to past and future events, as well as the present. Many students who are deaf-blind do not understand references to the future or past. Whatever the intention of the teacher, the student may respond to the communication as if it refers to the present. This may be frustrating to both teacher and student. Again, recognizing that the problem resides in the student's current abilities allows us to consider how and under what circumstances we should attempt to communicate or

request communication about past and future events.

What van Dijk (1986), Rowland and Schweigert (1989a), Writer (1987) and we (1984) have shown is that objects or tangible symbols can serve as a mediator in the denaturalization and decontextualization processes. Objects, used either as a step in the acquisition of communicative skills or as an end in themselves, have been quite successful. They provide a simplified and readily expandable and readable communication system, and a system which can be used by the student and the student's communicative partners. Anticipation shelves and object and picture calendars, which are ordered displays of objects or pictures representing the student's activities, provide a way to assist students to understand the organization of the day or even more remote intervals of time. But, more important, denaturalization and decontextualization can be encouraged through the use of progressively more varied and abstract objects (for some students leading to drawings, pictures, and printed words) and the sequential nature of shelves and calendars highlight the temporal relationship between activities.

However, like other activities, a lack of understanding of the theoretical underpinnings of the approach can lead to misapplication. Sometimes, the object, shelf, or calendar simply becomes another step in a task sequence, its function as a representation, its role in denaturalization, and its communicative value neglected. However, usually these objects and pictures serve as a nonlinguistic communication system understood by many at school, home, and in the community. They especially allow students with limited expressive skills to freely request and to select among options available to them.

Critical Issues

To communicate with all the members of a culture, it is necessary to use and understand their language. This is the most difficult step. That is not to say that many students do not use a few signs or occasional words to express requests or greetings. However, language abilities are much more than that. Acquiring a few signs for an immediately gratifying event such as food, drink, or a stimulating object does not imply readiness to acquire other language skills. However, I must confess to having little experience with students who are deaf-blind who gained true language fluency, and I have no experience in assisting individuals to retain language skills following later onset.

This leads me to the last portion of the paper in which I will identify some critical issues in communication, the resolution of which may result in enhanced communication skills for students in the future.

First, we need agreement regarding the meaning of commonly used terms such as "communication," "language," "symbol," and "intentional communication." Without agreement we are unable to communicate our successes and failures to others or to assist practitioners to understand what we mean. For example, does communication mean any behavior which can be given meaning by an observer or must there be a volitional component in the expression? Does language mean the ability to use words or signs or must there also be some non-imitative evidence of knowledge of syntax? Is a symbol a mental construct, an external representation of a mental construct, an act, an object, or all or some of the above? How do we define intentional communication among students who, because of sensory and motor impairments or age, do not demonstrate behaviors which identify intentional communication in typically developing toddlers.

Second, we need to know more about factors affecting the acquisition of communicative skills and, perhaps, learning in general in students who are deaf-blind. Arousal and attention, for example, affect the readiness and ability of students to acquire information. Yet, we have little systematically obtained understanding of strategies to optimize arousal level or how to gain, regain, and maintain attention.

Guess and his colleagues (1988) have demonstrated that many students who are deaf-blind with multiple disabilities spend little time at moderate and alert levels of arousal. Thus, the amount of time during the day when these students are able to participate and learn is limited. Yet, students are often regimented through activities without regard to state, and valuable learning time may be lost because the student's optimal time may not coincide with times the teacher is available. This is especially a problem when one-to-one teacher-student time is limited by necessity or design.

Any interaction characterized by joint participation requires joint attention. We know from studying typical development that lexical acquisition in its early stages occurs when child and adult are jointly focused on a topic, and the child is attentive to the adult's communication. If attention plays a similar role in the acquisition of nonverbal communicative skills, then the elucidation of strategies which effectively gain, regain, and maintain attention are essential.

Third, we lack an operational framework to account for learning differences not readily explained by the presence of impaired vision and hearing. Among these are the use of communication primarily for directive purposes, the substitution of repetitive and stereotyped behavior for exploration and self-guided learning, the apparent barrier in the acquisition of symbolic skills in play as well as language, and the appearance of seemingly inexplicable "splinter skills." Perhaps heterogeneity among students makes a developmental psychology of people who are deaf-blind impossible. But, we are at the point where further advances in intervention must evolve from knowledge of the cognitive strategies these students employ and how their strategies conform to or differ from the way other students acquire knowledge and skills. It is no longer cost effective to pursue theoretical efforts or to compliment ourselves on finding something that works. The clues are there, but the mystery remains unsolved.

Augmentative, assistive, and prosthetic devices have and will continue to have a major impact. However, technology offers tools not solutions. We have spent an inadequate amount of time determining who should use these devices, when, and under what circumstances. For example, there is no consensus over whether augmentative systems should be used to teach new concepts and new forms of communication or to facilitate the student's expression of concepts already known. In many cases, we do not know how the devices are actually used by the student. For example, is the student using a signalling device to communicate a request, to learn about cause-effect relationships, or simply to generate an interesting auditory or visual display? It is not sufficient for us to assume, without closer scrutiny, that the student's use and our interpretation are identical. We must also evaluate devices to establish whether they are limited to serving instrumental functions or if they allow the expression of a broader range of communicative intentions.

Not all issues regarding students who are deaf-blind will be resolved by learning more about the students. Personnel preparation remains a central issue. Previously, I

described a few areas in which misinterpretation of techniques may render them practically ineffective. Certainly, there is much room for upgrading our personnel preparation efforts. In interviews we conducted with teachers over the past several years, none indicated that they received much useful information regarding students who are deaf-blind from their formal education. They also reported little if any exposure to issues regarding the acquisition of communication skills. Much of what these teachers practiced was acquired from their professional colleagues. Even the speech-language pathologists had little background in nonsymbolic forms of communication. Thus, isolation from new developments and inaccurate transmission of information are substantial risks.

But, perhaps the biggest issue of all is figuring out where we fit as we move toward full or at least fuller inclusion of students with disabilities of all kinds in schools and the community. Most of us are used to and comfortable with the status quo. Not that we are by nature conservative, but we have designed some effective procedures for the contexts in which most students who are deaf-blind are now served. For example, by emphasizing one-to-one interactions, we have demonstrated that all students who are deaf-blind can communicate, and we have devised ways to structure the environment and to instruct those who interact with these students so that their communicative skills will continue to grow. But, we have ended up emphasizing the integrity of the individual's program with lesser concern for the value of the student's integration into society. The challenge is to reframe the issue from integrity versus integration to how may we re-shape our approaches so that all students who are deaf-blind, not just the most able, can reap the benefits of greater inclusion in society.

The challenge is similar in magnitude to that which we faced when services for students who are deaf-blind were first established. Twenty years ago, we led the way in establishing innovative categorical programs. We showed everyone that all students, regardless of their so-called "potential," benefited from educational programs. We concluded that students who are deaf-blind deserve and demand inclusion within the public educational system. We have now reached the next step.

Obviously, communication will play a significant role in the inclusion of students who are deaf-blind in schools and society. There are a host of new issues on the horizon in assessment and intervention and in personnel preparation. We must consider how students will acquire communicative skills in new contexts and, perhaps, with new mentors. In assessment, we will need to redefine functional communication skills. We must also consider how to prepare professionals and peers to instruct and interact with students who communicate in unconventional ways. Eventually, we will need to turn our analytical skills, honed in endless hours of videotape coding and task analysis, to the small issues on which the effectiveness of integrated programs may turn. For example, what contexts, materials, group sizes, ratios, and levels of structure best facilitate interaction, communication, and learning in students who are deaf-blind and among their peers? We will also need to find efficient and effective ways to teach peers (and sometimes teachers, too) that there are ways of communicating other than talking and grabbing.

I don't have the answers. However, I do know that we are at a crucial juncture. We must either lead by showing we can apply the knowledge we have accumulated to the changing contexts where students who are deaf-blind will be served and expected to

function, or we can relegate our collective wisdom to the archives while others take the lead. We cannot ignore and, in fact, should capitalize on society's growing commitment to diversity in schools, the community, and the workplace.

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COMMUNICATION: REACTION

Steven Collins

Abstract: We must recognize that communication includes many aspects: facial expression, body language, and cultural rules. From the earliest ages, people who are deaf-blind must be exposed to their "natural" language. They have an internal language and a powerful need to communicate. Those established in the deaf-blind community have the ability to open the world of communication to culturally isolated deaf-blind individuals. Researchers, parents, and professionals need to build rapport with people who are deaf-blind (instead of "using" them for research purposes). They need to learn to communicate on all levels with them. Most of all, they need to listen to and learn from those who are deaf-blind, respecting their experiences and learning their "natural" language.

I want to share with you what a thrill it is to be here at a symposium where we have so many people—professionals and parents—together. Here we are in a forum where a variety of opinions are welcome even though there are strong opposing views. We are all meeting together to benefit the future of children who are deaf-blind. After my presentation some of you will agree with what I have to say, and some may disagree. First, however, I want to tell you where I'm coming from, a little bit about my background. I don't have years of experience as a researcher or as a scientist; however, I have been involved with the deaf-blind community all my life. I want to speak to you from the perspective of a deaf person who has been involved with people who are deaf-blind.

I would like to speak about the great variety we find in this group of people. There are those who have Usher Syndrome Type I, and there are those who have Usher Syndrome Type II. There are those who are deaf-blind and have additional disabilities. Dr. Stillman's paper was narrowly focused on one small segment of people who are deaf-blind: those who have developmental disabilities in addition to being deaf-blind. I would like to broaden the picture to talk about other parts of the spectrum. It is important to understand that there are people who are deaf-blind out there who go on to pursue higher education: college, graduate degrees, and doctorates. Many of these are quite successful, especially when it comes to communication.

When we talk about communication, it's important to talk about language. When we talk about language, it's important to consider where language comes from. We have heard some discussion from parents talking about language, but are they talking about a *natural* language? We need to give some consideration to this because, when people talk about natural language, they only think of English, including speech, signed English, or an English-imposed system, even if they accept sign language. However, a system that is really natural comes from within the person. A person who is deaf or deaf-blind with Usher Syndrome may grow up in a residential school for the deaf. These people do not have English as their first language: instead, they use ASL, American Sign Language. Many people use the expression "Sign Language," but it is important that when we use it we recognize we are talking about *American* Sign Language, a language that is natural to America.

We see this problem in Stillman's paper. He does not understand all that language includes. It includes so many factors—facial expression, body language, and cultural rules.

One of the greatest frustrations we find in communication with people who are deaf-blind is that they have not been exposed to the proper language. Hearing people, as infants, are exposed to language while in the mother's womb. Before the age of one, they learn to babble and they will continue their development appropriately. Children who are deaf have an inner readiness for a language if exposed to it, but these children have to go along with the language that is available. If the infant is not stimulated with the proper language, it becomes very frustrated. Later on, there can be communities established to provide a shared means of communication. Inadequate research has been done in this area, and those who have been doing the research don't have the language of the population we are talking about. Their language may only be signed English. As a result, they may not have the full spectrum of communication.

Dr. Stillman, in his presentation, mentioned the need for arousing and maintaining attention for effective communication. This is also true with internal natural language. In order to accomplish this, the speaker needs to be *fluent* in the language, not just *good enough*. If there is fluency, then we will see this advantage carry over into the research. This gives us cause to wonder about the researcher who is not doing an indepth study with language. This person may not have good language skills or knowledge of appropriate physical contact or the appropriate way to relate. People who do have these skills are rare.

Let us talk about the issue of arousing and maintaining attention in regards to children and communication. Even the word "communication" is vague. It includes aspects such as feeling, touching, facial expression, body movement, and the general feeling of rapport. I strongly encourage parents of children who are deaf-blind and professionals to contact adults who are deaf-blind who have a strong language, whether it be, Signed Exact English or American Sign Language.

I would like to point out that there are deaf-blind communities around the country. Even in Washington, D.C. there are local organizations such as MWADB (Metropolitan Washington Association of the Deaf-Blind). In Seattle, there is WSADB (Washington State Association of the Deaf-Blind). In Pittsburgh there is WPADB (Western Pennsylvania Association of the Deaf-Blind). Many other large urban areas have clubs for those who are deaf-blind. Certainly I won't have time to name all of the communities, but I think it is important to give credit to all of them. I believe language is what causes us to feel like a family, to become very close. We socialize and have monthly functions or meetings. Unfortunately, we don't see parents or professionals involved, and we see that they don't know what is really going on. They end up missing out on many aspects of the deaf-blind community by not being involved.

One of the most important aspects of a deaf-blind community is the culture. Parents and professionals cannot just go into the deaf-blind community. One has to be invited or asked to come. If you can find entry into this culture you will find plenty of meaningful data to help you with your research, but to come in as an outsider and to impose your way in is not welcome at all. It is very important to build rapport with the person who invites you in. Again, my focus isn't only on people who are deaf-blind with developmental disabilities but on a broader spectrum that includes Usher Syndrome

Type I and Usher Syndrome Type II, from infants to the elderly.

When we talk about the deaf-blind community and their language, ASL, we must also discuss the oppression which has been in existence for many years, in both the deaf and deaf-blind communities. As Americans, English, or the American culture, is always being imposed upon us. One of the "hot' topics today is multicultural diversity. Some things I can see have not yet changed, but it is now time for change. Early research of the fifties, sixties, and seventies was done on hearing people, then deaf people, and, always as the final category, people who are deaf-blind. People would tend to analyze the issues of those who are deaf-blind only when comparing them to the issues of those who are deaf. Now that we are in the nineties, we need to take a look at the researchers, the people trying to analyze and gather information. We need to find out if they have a language base or the necessary background. For example, we have yet to see adequate research on the tactile methods used by people who are deaf-blind. Several people are successful at communication, especially those who have graduated from the Perkins School. My point is that researchers should not be *using* these people; they should be *working with* them. As a deaf person, I have dealt with, communicated with, and enjoy a rapport with hearing people. They feel able to ask me questions about language or culture because I have "invited" or "welcomed" them. I want to see more research done and more papers being published. I also want to see publications with adequate input in them from successful adults who are deaf-blind.

At this time I would like to share one success story of the deaf-blind community. A man in his 40s arrived from another country in which no one had understood the etiology behind his deaf-blindness. For 40 years, he had been considered to be a person with many limitations—even developmentally disabled. He was shipped off to the United States and found himself in a town which had a large deaf-blind community. He was welcomed into this community. Although he wasn't able to use American Sign Language or even an expressive form such as body language because he had been confined for 40 years, he still had an internal language and a powerful need to communicate. Throughout his life, people who dealt with him had not stimulated him. However, when he got involved with the deaf-blind community, he entered a new situation. At a deaf-blind camp, he encountered a deaf person whom he had never met before. When these two people met, language occurred successfully. It turned out that they were intelligent people in their own fields. They could communicate. The person wasn't developmentally disabled at all. In fact, there were no additional disabilities. He was just a regular person with Usher Syndrome. Many of the most valuable years of his life had been wasted because of not having his language needs recognized. For hours upon end, these two individuals were able to talk and communicate and participate in other activities. I have since seen this particular person communicating fluently. He was able to communicate because he had an internal language readily available.

Some of you in our audience are parents, and some of you have been involved in the professional arena. You can't help but notice the problems of people who are deaf-blind. When I talk to you, I speak as a deaf person. I think I can share with you a parallel. We can look at what has happened with people who are deaf over the years and see a striking similarity. For years, people didn't recognize the potential of people who are deaf.

The problems we face are significant. We all can do better. One important way to overcome these problems is to support and learn from the deaf-blind community.

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PERSONNEL PREPARATION: PRESENTATION

Barbara A.B. McLetchie

Abstract: We are faced with dwindling numbers of faculty and an erosion of programs, especially in the fields of low-incidence disabilities. A 1992 national survey indicates that during the next decade there will be a need for 960 new teachers of students who are deaf-blind. To meet this projected need, four areas deserve attention. First, through federal funding, we must establish innovative personnel preparation programs that include the ideas of shared internship sites, connected, rather than competitive, programs, and creative placements and cooperative follow up of graduates. These innovations will motivate young people to choose and stay in careers in this field. Second, we must recognize and prepare for the ever-expanding roles of teachers as coaches of paraprofessionals and professionals, as family interactors, and as team players. Third, we must encourage establishment of national standards—a necessary foundation for determining "best practices" and for clarifying and elevating professional identity. These standards should be incorporated into grant proposals for personnel preparation programs. Fourth, we must encourage personnel preparation programs to make meaningful and practical links with adult services. To achieve this, as part of their preparation, future teachers must have real experience with adults who are deaf-blind.

Introduction

In thinking about my charge to talk to this symposium regarding the present picture in personnel preparation in deaf-blind education and to make the future the centerpiece of this presentation, I realized that I could not negate or forget the past. My own retrospective view begins in 1969 when I graduated from the Boston College and Perkins School for the Blind Teacher Training Program. I do not intend to give a litany of the high quality teacher preparation programs in deaf-blind education which dotted the country in the 1970s. Suffice it to say that personnel preparation in the 1970s was better than it is today.

The 1980s witnessed less federal involvement in all aspects of education. Immediate effects in special education teacher preparation at the university level were seen in dwindling numbers of faculty and an erosion or obliteration of programs, especially those in low-incidence disabilities, with programs in deaf-blind teacher preparation often the first to go. To paraphrase Herodotus, if we do not learn from the present and the past, the future is like a tidal wave waiting to destroy us. We have now learned from the last decade that lack of federal support specifically targeted for teacher preparation in this field resulted in too few teachers for too many children too widely dispersed throughout the country.

However, I believe that this symposium funded by the federal government may be a strong signal that the future of services for individuals who are deaf-blind will be more promising. The Office of Special Education and Rehabilitation Services, in collaboration with persons who are deaf-blind and their families, service providers, state and local governments, and private enterprise, can be a force of positive change in personnel preparation as well as in the other focus areas of this symposium.

We must listen to the lessons of the past. Without federal support, professionals, families, and individuals who were

deaf-blind lost unity, and services became fragmented and inadequate. States through their respective Comprehensive System of Personnel Development (CSPD) efforts have not been able to meet the needs of personnel development in this field. The number of students who are deaf-blind in each state is low in comparison to students with other disabilities, and low numbers often equal low prioritization. However, the federal government must not merely maintain its involvement: it must expand services to individuals who are deaf-blind and their families. In personnel preparation, creative requests for proposals authored by the federal government and backed by adequate financial awards can have great power.

In this presentation, I will address four areas which deserve our attention:

1. We must give impetus through federal funding to universities to establish innovative personnel preparation programs which motivate young people to choose and stay in careers in deaf-blindness.

2. We must recognize and support the ever-expanding roles of teachers as more students who are deaf-blind are included in their home schools and communities and as more students come from diverse family backgrounds and cultures.

3. We must encourage national standards which are the necessary foundation for "best practices" for teachers of students who are deaf-blind.

4. We must encourage personnel preparation programs for teachers of students from birth to 21 or 22 years to make meaningful and practical links with adult services.

Major Issues in Teacher Education

Before we focus on these four areas in personnel preparation, let us look at the large picture of teacher preparation of which preparation to teach those who are deaf-blind is a part. Because of the national commitment to provide education to students who are deaf-blind in regular schools, a picture of the whole, using a wide angle lens, is important.

Without question, preparing men and women to become high quality teachers of our nation's children, whether or not these children have disabilities, is vital to our society. Teachers play major roles in our children's destinies. America 2000 challenges our country to improve our schools. Despite the importance of teacher education, our profession is held in low esteem by university administrators; teachers receive low societal regard; and the teaching profession imposes inadequate standards for the graduates of teacher education programs (Brandt, 1991).

There are issues in teacher education which create debate. There are no simple answers to these questions: Should teacher preparation exist at all? How much should pre-service teachers be trained in pedagogy as opposed to liberal arts? Should teachers be trained at the graduate or undergraduate level? (Holmes Group, 1986). Should we hold the teaching profession to standards as high as for other professions such as law or medicine (Goodlad & Keating, 1990). Should teachers be required to take competency tests? Is field-based experience valuable? Do teachers learn what they need to know to deal with the real problems of today's schools? Should regular education merge with special education? (Stainback and Stainback, 1989). Should all teachers be prepared to teach all children? (Lilly, 1988; Pugach, 1988; Stainback & Stainback, 1989).

It would be pure escapism to avoid the issues by not attempting to answer the questions posed here. Therefore, this paper is based upon the following assumptions:

1. Teachers can be prepared. Teacher training makes a positive difference.

2. Special education teacher preparation should continue to exist. "Not all teachers are equipped to teach all students" (Kauffman, 1989 p. 257). Kauffman further makes the point that this assumption is one of the foundations of special education that has existed for a century. However, special education must exist cooperatively with regular education preparation efforts. Both need to influence each other and solve common problems together in both service delivery and personnel preparation.

3. Teacher preparation in this field requires unique training which expands upon and integrates several areas of teacher education. To assume otherwise is to trivialize the devastating and synergistic effects of combined losses in vision and hearing upon all aspects of human development. The teacher of students who are deaf-blind must creatively integrate and adapt knowledge and experience from regular education, and from special studies in blindness and visual impairments, in deafness and hearing impairments, in severe disabilities, and in the field of deaf-blindness to meet the individual needs of each learner who is deaf-blind.

Existing Training Programs

Nationally, over 1200 institutions are engaged in teacher education, graduating 500 thousand new teachers per year (Doyle, 1990). Aspiring teachers attend a variety of different institutions and can choose from a multitude of specialty areas ranging from elementary education to vocational education. In essence, teacher preparation is a complex enterprise.

A view of teacher preparation in deaf-blind education shows that there are currently four federally funded programs under the Division of Personnel Preparation that prepare teachers specifically for working with infants, children, and young adults who are deaf-blind. There are two survivors of federal cutbacks on the east coast: Boston College, which I represent in Massachusetts, which has received federal support since 1971, and the program coordinated by Dr. Roseanne Silberman at Hunter College in New York, which has been federally funded since 1974. These programs graduated 10 and 8 teachers respectively, in 1992. The University of Arizona has a program in multiple disabilities and dual sensory impairments which graduated one student in 1992. This new program is coordinated by Dr. June Downing and has been funded for two years. The program at Texas Tech, coordinated by Dr. Roseanna Davidson, graduated seven students in 1992. Utah will enroll eight students in February of 1993 in a program in dual sensory impairments. This program is directed by Dr. Dick Kiefer-O'Donnell and was federally funded this year under a special projects grant to the Utah State Department of Education. It will use the resources of three universities: University of Utah, Utah State University, and Brigham Young University.

The Conrad N. Hilton Foundation in its project with Perkins School for the Blind provides funds for six personnel preparation programs. San Diego State University's program is coordinated by Dr. Kathee Christensen, and the program at Michigan State University is coordinated by Dr. Lou Alonso. The University of Alabama provides training in this field with its vision program. This program is coordinated by Mary Jean Sanspree. Illinois State University will begin a teacher preparation program coordinated by Dr. DeMario, in the summer of 1993 with a Hilton-Perkins grant.

Boston College and Texas Tech also receive funds from Hilton-Perkins to expand teacher preparation in this field.

These privately supported programs, excluding Boston College and Texas Tech which were counted under federal funding, graduated 18 teachers in 1992.

Future Demand for Teachers of Students who Are Deaf-Blind

There is a paucity of research on the training of teachers working with students who are deaf-blind and the demand for trained teachers. A national survey done in 1989 (Maxon, Tedder, Lamb, Geisen, & Marmion) of 124 teachers working with a total of 1,791 students with disabilities of whom 26% (568) were students who were deaf-blind revealed that there will be an ongoing need for services for school aged students who are deaf-blind despite the fact that members of the rubella population are now adults. Data from this survey indicate that students who are deaf-blind were "subsumed in the multihandicapped category" (Maxon et al., 1989, p. 45) because the teachers were working in programs for students with multiple disabilities. Results further showed that 38% of these teachers had bachelor's degrees, 54% held master's degrees and 2% held doctoral degrees. Only 12% of the teachers had certification in the deaf-blind area. However, almost half of the teachers reported certification in more than one area. Because most states do not have certification in the deaf-blind area, the data do not accurately indicate personnel preparation in this field.

A recently published study of low-incidence special education teacher preparation (Bowen & Stearns, 1992) from Illinois State University reported difficulty in identifying teacher preparation programs "particularly in the areas of deaf-blind, hearing-impaired and bilingual education" (p. 11). This same study noted the discontinuance of programs in the deaf-blind area that had been funded through the Division of Personnel Preparation. This report clearly shows that we in personnel preparation need to share information better. The National Clearinghouse on Deaf-Blindness could assume a coordinating role in this endeavor.

In the fall of 1992, a national survey was done to develop a clearer picture of services for persons who are deaf-blind and to determine the projected need for qualified personnel. This was a telephone survey of state and multi-state project coordinators under Section 307.11, followed by a mailed survey to check for accuracy of responses (McLetchie, Butterfield, & MacFarland, 1992). The 42 coordinators that responded represented 45 states, the Virgin Islands, and Puerto Rico. A total of 6,741 students were reported who were deaf-blind and ages 0 to 21 or 22. These students were being served by approximately 3,668 teachers. The project coordinators estimated that only 6% of those teachers had received preparation in the deaf-blind field. Thirty-one of the 42 respondents, an overwhelming percentage, said that their state or geographic region needed a personnel preparation program in the deaf-blind field. Nineteen of the 31 project coordinators wanted the personnel preparation programs in their own state. The project coordinators estimated that there will be a need for 960 new teachers of students who are deaf-blind over the next decade.

The few personnel preparation programs in the deaf-blind field and the small number of teachers graduated with high level training in this field may not equal the complex enterprise Doyle (1990) refers to in regular education. However, the small number of programs and the high number of unqualified teachers certainly create complex

problems in educating children who are deaf-blind.

Because of the inadequate number of teachers specifically prepared in this field and the ongoing need for teachers of students who are deaf-blind, the dispersion of the deaf-blind population, and the challenge to include students who are deaf-blind in regular education settings, the number of high quality teacher preparation programs supported by the federal government must be increased. The Conrad N. Hilton Foundation in its project with Perkins School for the Blind demonstrates that private funds are being used to support six teacher preparation programs specifically for those who are deaf-blind. This effort has laid the groundwork for more federal involvement and is certainly in keeping with America 2000 which encourages private enterprise to invest in education. However, because deaf-blindness is such a low-incidence disability and the challenges of serving persons who are deaf-blind are so great, it is imperative that strong federal support occur in cooperation with state and local initiatives and private enterprise. With the present scenario in mind, I wish to direct our attention to the future. Previously, I mentioned four areas in which we must concentrate our effort. The first of these concerns teacher preparation programs.

Federally Funded Programs in Universities

In the future we see that we must have at least 10 federally funded teacher preparation programs in the deaf-blind area, strategically placed throughout the country, graduating a total of 80 to 100 graduates per year. (Future planning requires prediction. The coordinators of state and multi-state projects under Section 307.11 estimated a need of 967 new teachers over the next decade.) Project coordinators are in excellent positions to determine general geographical areas in which the personnel preparation programs would be best placed to ensure that children who are deaf-blind are served adequately. For example, the recent survey of project coordinators (McLetchie, Butterfield, & MacFarland, 1992) and supporting interviews with two TRACES (Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments) regional coordinators indicates that the Midwest is in great need of a teacher preparation program(s).

Requests for Proposals (RFPs) must be specific to personnel preparation in the deaf-blind field. These RFPs can be tremendously helpful in helping university deans and presidents recognize and value teacher education in fields of low-incidence disabilities, including deaf-blindness.

Moreover, teachers of the future will need to be better educated than ever before. Therefore, these personnel preparation programs should be graduate level programs (Holmes Group, 1986). Appropriate universities for such programs would be those that already have strong expertise in regular education and have demonstrated experience in teacher preparation in at least one, if not all, of the following: vision impairment, severe disabilities, and/or hearing impairment.

This recommendation has educational and practical validity. Teachers of students who are deaf-blind must integrate knowledge from regular education and specialty areas, and then adapt that knowledge to each child's unique needs. Dreams of the future are always tempered with reality. Over the past decade, many universities have suffered debilitating losses in numbers of special education faculty and elimination of special education programs. New programs and options in special education including

deaf-blind education need to dovetail with each other and with regular education. If a university cannot provide the necessary coursework by linking and overlapping within its own curricula, mechanisms for partnerships with other universities should be established which could include satellite broadcasts and other forms of long-distance education. This concept may be easy to implement in state college and university systems, but may be more difficult at private universities, which tend to claim ownership of programs.

In essence, personnel preparation programs of the future "cannot be successful as separate islands" (V. Hart, personal communication, October, 1991). With careful long-range planning and federal commitment specific to deaf-blindness, personnel preparation in the field of deaf-blind education may be able to survive and flourish in the future. Stability can be safeguarded by the interconnectedness which preparation in this field can develop with both regular education and other focus areas of special education at a single university or a group of universities sharing resources.

Connected Programs, Shared Internship Sites and Research

The programs that prepare teachers of students who are deaf-blind must not compete with each other. This means that RFPs should be cycled appropriately and projects be required to demonstrate collaboration. This collaboration, perhaps best included in the plan of operation of grant proposals, is essential for developing evolving standards to ensure that students who are deaf-blind are well served, in establishing first class practicum and internship sites, and in sharing in much needed research in teacher education.

All of us who prepare teachers to work with students who are deaf-blind and their families are in need of internship sites in regular schools. These require two essential players: a student who is deaf-blind and a cooperating teacher who is trained and experienced in teaching students who are deaf-blind. Although more students are living and being educated in their home communities than in the previous decade, the reality is that their teachers are generally not qualified in deaf-blind education. Teacher preparation programs must work in symphony to identify and establish high level practicum experiences in regular schools. This will require university personnel to spend more time in schools creating partnerships with administrators and practitioners. Targeted sites should provide excellent information for university and school personnel to evaluate as a team. Use of videotapes, broadcasts from sites to universities, onsite observations, and co-teaching by university faculty and practitioners will provide much needed and valuable data on strategies for including students who are deaf-blind in regular schools and community-based settings.

We must also research the effects of inclusion on the learner who is deaf-blind.

Creative Placement of Graduates

Establishing innovative internship sites should include placing graduates of our programs where they are most needed and also require university personnel to continue to support and mentor graduates after degrees are conferred. Perhaps our graduate students, or at least a stipulated number or percentage in each of the federally funded personnel preparation programs, should be required to take positions where the teacher shortages have the greatest negative impact upon children who are deaf-blind and their families. This concept would require additional financial incentives. Placements would include both rural and inner city settings where students who are deaf-blind

may be at risk for being inadequately served. This effort will demand connectedness of the teacher preparation programs nationally and input from the coordinators of state and multi-state programs under Section 307.11 and TRACES, and state and local education authorities.

The ultimate recipients of teacher preparation programs are students who are deaf-blind. Ongoing and onsite follow up of graduates may help to ensure that children who are deaf-blind receive high quality services. Cooperative follow up of graduates by university personnel from all federally funded university programs would allow graduates the choice of going to geographic areas of the country, different from the one in which they were trained. The benefits would be the establishment of cutting edge internship sites, provision of expertise to local schools, and establishment of a job bank in deaf-blind education that spans the country.

Summary

The federal government can be an agent of positive change by providing incentives to universities to offer programs in deaf-blind education which expand upon and are interwoven with other areas of teacher education at one university or a few universities which function as a consortium. The federal government can encourage positive change by providing financial incentives for aspiring teachers and by stipulating that a number of high level graduates be placed in settings where they are most needed after they graduate. Through strong federal support, university leadership will learn to place value upon shared research endeavors and upon the time professors spend in schools helping to improve educational services in a partner relationship with teachers (Frieberg & Waxman, 1990).

Expanding Roles of Teachers

Teachers of infants, children, and young adults who are deaf-blind presently assume roles that transcend school settings. Working with families whose first language is not English, providing educational intervention in neonatal units, and meeting the challenge of serving children who are deaf-blind and medically fragile, including those who have AIDS, are some examples of the variety of new roles that have evolved over the past few years.

The Teacher as a Coach of Para-professionals and Professionals

A major responsibility of the teacher in the next decade will be to act as a coach to other professionals and paraprofessionals who will have the tremendous task of integrating and including children and young adults who are deaf-blind into school and community activities. Without question, most children who are deaf-blind can go to regular school and make friends with nondisabled peers. They can fully participate in community activities. However, they will need individualized support. Although this support person might be called by different names—intervener, integration facilitator, interpreter-tutor—the existence of this support person is crucial. A person who is deaf-blind requires someone to act as interpreter of life's events. To assume otherwise is to negate the highly complex problems created by combined vision and hearing loss. Anyone who has had the opportunity to know adults who are deaf-blind and deaf recognizes how vital adequate assistance is for achieving independence.

As teachers become teachers of other professionals and paraprofessionals in the next decade, they fortunately will have the materials produced by the Deaf-Blind Project of the American Foundation of the Blind to

use as teaching tools. These resources have the potential of providing essential background information and strategies from which individualized support and interventions may evolve. TRACES and the National Information Center on Deaf-Blindness will also play crucial roles in assisting teachers in this important endeavor of coaching professionals and paraprofessionals so persons who are deaf-blind may be included in their communities.

Personnel preparation programs will need to redesign and try to determine the qualities that enable a teacher to be a competent teacher of other professionals and paraprofessionals. It is highly conceivable that a teacher who is an excellent teacher of children might be an inadequate teacher of adults.

The Teacher as Family Interactor

The Individuals with Disabilities Education Act (IDEA) mandates that parents are full and equal partners in the educational process. However, the intention of the law is not always put into effective practice. The quality of life indicators that parents of children with dual sensory impairments consider to be important (Giangreco, Cloninger, Mueller, Yuan, & Ashworth, 1991) and the concept of personal futures planning (Mount, 1992) are examples of recent work in the field which help set future directions for teachers to attain effective and sensitive involvement with families.

The future will require teachers to have skills that help them understand what families consider to be important to life and how to link these quality of life indicators to educational process. Choosing Options and Accommodations for Children (C.O.A.C.H.) is a useful vehicle for involving families in the education of their children. Most families and professionals would agree that having a safe home; accessing a variety of places and engaging in meaningful activities; having meaningful relationships; having choice, control, and independence that match one's age; and being safe and healthy (Giangreco, Cloninger, & Iverson, 1992) are strong determinants of one's quality of life.

Mandated services for infants and toddlers (0 to 3) will require teachers to know how to link and build upon early intervention services that may already be well established. In other cases, teachers will have the task of creating early intervention services. It is interesting to note that 43% of the coordinators of state and multi-state projects under Section 307.11 said services to the infants and toddlers who are deaf-blind were adequate, and about 40% said services were good, with 17% ranking services to infants and toddlers as inadequate (McLetchie, Butterfield, & MacFarland, 1992). Teachers will need to learn how to successfully transition children to educational settings from home-based or early intervention centers.

Because more children who are deaf-blind are living and attending school in their home communities, teachers will have to work with families in partnerships to include the child who is deaf-blind in the family and community settings. Involving siblings so that normal interactions are facilitated is also important. The concept of inclusion is holistic and therefore encompasses the home and community environments. Helping families to access in-home support and respite services is a role teachers assume now and this role is likely to increase in the future. Home support may be a particularly critical issue for families whose children are transitioned from residential schools and for those families whose children have complex medical problems.

Family diversity. An increasing challenge of the future will be for teachers to be

flexible, sensitive, and responsive to families of diverse ethnic backgrounds who have varied perspectives and values. These skills are impossible to teach from a textbook or lecture. The United States has changed from a country which took pride in being a melting pot to a country which celebrates differences (Schlesinger, 1992). How we incorporate this philosophical shift into the educational system is pivotal to the way we prepare teachers to involve all families in the education of their children.

Although most departments or schools of teacher education include coursework on diversity, a study of over 700 teachers from the National Center for Research on Teacher Learning showed "troubling" results. Although participants had taken coursework in diversity, most were unable to transfer theory into effective practice (Kennedy, 1991). Just as including students with disabilities should be embedded in many courses as a recurring critical issue, perhaps the issue of diversity should not be a separate course but should instead be incorporated into several courses. Again, the federal government can be an agent of positive change. Standards dealing with diversity issues should not be linked with one course but should be a recurring theme in several courses including student teaching experiences and accompanying seminars. The inclusion of nondiscrimination policies in grant proposals will not be adequate proof in the next decade that universities are meeting the needs of diverse learners and their families.

Recruitment and placement. Diversity in teacher education in the next decade will also encompass the active recruitment of minority students. Given that our graduates are often our best recruiters, incentives which encourage graduates to take positions in inner cities would be an indirect but potentially powerful recruitment tool. The incentive could be in the form of a stipend that continues for a school year after graduation or a larger stipend the student receives during graduate work with a commitment to work in an inner city after graduation. University personnel would also be required to maintain an active commitment to the graduate which would include time in schools in a partnership role. As referred to earlier, the connection among teacher trainers at 10 programs across the country would allow university faculty to share in the active follow up of graduates. That is, the program geographically closest would be most likely to follow up on the graduate working in an inner city. For example, if a graduate from Utah wanted to work in an east coast inner city, it would be logical that Hunter College or Boston College provide onsite support to the graduate.

We now have state-of-art data on numbers of deaf-blind children in this country. A goal of the future must be to ascertain those who are underserved. Perhaps the National Clearing House on Deaf-Blindness could establish a data base which shows placement of students who are deaf-blind and the type of placement. Excellent research (Goodlad & Keating, 1990) demonstrates that the majority of children in inner-city schools do not receive equal and high quality education. This statement is also probably applicable to students who are deaf-blind. It is also possible that students who live in inner cities are referred to separate special education programs and schools. This concept of providing incentives so graduates are encouraged to work in inner cities should also apply to rural areas where students who are deaf-blind are underserved. In essence, recruitment plans in proposals should include placement of graduates where students who are deaf-blind are disadvantaged and the establishment of ongoing partnerships with schools.

In teacher preparation programs, diversity should include minority students, students with disabilities, and parents. For example, the program at Boston College last year was enriched greatly by the participation of a graduate student who is deaf-blind as a result of Usher Syndrome and a student who is a parent of a child who is blind and has multiple disabilities.

The Teacher as Team Player

"Teaming," "collaboration," "trans-disciplinary team," and "team approach" are words that convey positive connotations and are used with a high degree of frequency when we discuss providing high quality services to persons who are deaf-blind. However, we do not, in my opinion, adequately prepare teachers with the necessary interpersonal skills to be effective team players. The present and future demand careful research on what variables make a successful team on which the child who is deaf-blind is the most important player. In teacher preparation, we must utilize other disciplines such as counseling psychology and social work, which can help teachers evaluate and improve their interpersonal skills and ability to understand group dynamics. We also must model teaming in some university-based coursework, which will require abandoning the lecture format and involving our graduate students in working in teams in classes at the university and in practicum experiences. This concept has a pragmatic approach but is most difficult when there is an incredible pressure from deans to have high enrollment in university courses.

Competitive priorities in RFPs should include innovative approaches for preparing teachers with high level skills to function as effective team players and as advocates for the person who is deaf-blind, the central team member. We are in need of models that demonstrate effective teaming. Group analysis of videos might be helpful at the university level but actual practice as a participant in the process is essential. Teacher educators in the next decade will need to be more vigilant about teaching problem-solving skills. Innovative approaches could include providing some coursework in schools as opposed to university lecture halls.

Summary

As roles of teachers expand and there are new causes of deaf-blindness to challenge us, it is the responsibility of teacher educators to expose all of our graduate students to the ever-widening responsibilities of teachers. Each aspiring teacher should have coursework and experience related to the range of abilities in the very heterogeneous population of individuals who are deaf-blind. Teacher educators also have a responsibility to help teachers evaluate what their strengths and weaknesses are so they can seek further training in some areas or choose jobs in subspecialties in the field of deaf-blind education in which they have the greatest strength and motivation. For example, working with an adolescent who has Usher Syndrome is very different from working with an infant who is deaf-blind and medically fragile. Teachers admittedly have different skill levels and interests, but they all should be highly competent in working with families and in effecting positive team interactions.

National Standards

The issue of standards or lack thereof also plagues regular education. John Goodlad's comments about standards in regular education also apply to the education of students who are deaf-blind. Standards are waived when there is a shortage of teachers. This practice would not occur in other

professions such as law or medicine (Goodlad & Keating, 1990). Teacher preparation requires redesign and renewal. Teachers are being graduated without the skills needed to manage complex problems. As Goodlad stated in recent interview, "There is a lack of connectedness between the schooling enterprise and the preparation of those who staff it" (Brandt, 1991, p. 5).

We must all work for the establishment of national standards in deaf-blind education. Standards can help ensure that students who are deaf-blind not only have access to education but that their education is of high quality. Standards also can elevate our profession and be a force for professional identity. Although standards are not the only solution to the multitude of problems teachers confront, standards are the vital foundations from which "best practices" emanate. Strong standards can also be self-evaluation tools for teachers so they can be ongoing learners who pursue study and research.

A recent national survey of the coordinators of state and multi-state projects under section 307.11 clearly shows that most students who are deaf-blind are being taught by teachers not prepared for educating children who are deaf-blind (McLetchie, Butterfield, & MacFarland, 1992). Even if the assumption is made that more teacher preparation programs will be established over the next decade, a critical shortage of qualified teachers will persist because more children who are deaf-blind will be attending their neighborhood schools. There is a need to establish standards and disseminate them nationally, so at the very least, administrators who hire teachers not trained in deaf-blind education will have a composite picture of what a teacher of students who are deaf-blind should look like. Therefore, national standards can also be incidental learning materials on the problems imposed by combined vision and hearing impairments. Additionally, the standards should be incorporated into grant proposals for personnel preparation programs.

Standards should not be teacher centered but should focus upon the relationships between teacher and child, teacher and other personnel, and the teacher and families. For example, if we agree that teachers' roles in the next decade will include teaching others how to be support persons for the student who is deaf-blind who is included in regular school, a standard might be stated as follows: The teacher is an effective coach of the paraprofessional who facilitates the active participation of the student who is deaf-blind in school and social settings.

Among these standards should be a time frame in which a teacher should be required to actually teach children who are deaf-blind in order to be considered a master teacher of students who are deaf-blindness. This means that those of us involved in personnel preparation will need to maintain an active connection with graduates after degrees are conferred to provide support and ensure quality. This effort should be done in concert with TRACES and coordinators of state and multi-state projects under section 307.11, and with university personnel in deaf-blind education who are in close geographical proximity to the new practicing teacher. Improved technology including use of videos and conference calls can make active follow up a reality.

Establishment of standards from which specific competencies are generated should involve teacher trainers, teachers from regular education, teachers of students who are deaf-blind, administrators from regular and special education, parents, deaf-blind adults, and representatives from services for adults who are deaf-blind.

Standards should be endorsed by a national organization or organizations. However, these standards should not lead to separate certification in each state. State certifications in deaf-blind education could lead to a bureaucratic maze from which there is no exit. Teachers of children and youth who are deaf-blind have preparation which exceeds other specialty areas. It is most practical for graduates to be certified in another area such as severe disabilities, vision impairment, or hearing impairment and then be endorsed in deaf-blind education by a national organization.

Active and ongoing involvement from a national organization(s), from committed team participants, and from evaluation criteria that include standards in federal requests for proposals in personnel preparation should help to ensure that standards generate "best practices," motivate quality educational services, and create a network of educators with a professional identity.

Adult Services

McNulty (1992) recently stated that if educational services are in their childhood, services for deaf-blind adults are in their infancy. What a cruel paradox. McNulty's statement is supported by a recent survey of coordinators of state and multi-state projects under section 307.11 (McLetchie, Butterfield & MacFarland, 1992). Although 19 coordinators said educational services were adequate or good, 23 of the 42 respondents said services for adults were either nonexistent or inadequate. A scene of the future depicts strong and evolving links between personnel preparation and adult services for persons who are deaf-blind. If education is to be life long as articulated in America 2000, we have to stop thinking in terms of birth to 21 or 22 years.

Teachers of the future must have real experience with adults as part of their preparation. Adults who are deaf-blind should be valued instructors in teaching modules in university-based courses. Although the actual presence of a deaf-blind instructor in a classroom is preferable, satellite interactive broadcasts could be utilized or videos could be used. Aspiring teachers should be required to spend part of their practicum requirements in adult services. Without a clear perception of the lives of adults who are deaf-blind, there is no way teachers can anticipate and plan for the future of the children they serve.

Despite years of effort spent in teaching learners who are deaf-blind how to communicate effectively and make choices, many of our students leave school and enter adult life where there are no choices other than loneliness and boredom. We have opened the doors of neighborhood schools. In the next decade we must work creatively to provide inclusive communities for adults who are deaf-blind. In the education of children who are deaf-blind we, as a profession, have always recognized the importance of working with parents. We must give comparable recognition to working with adults who are deaf-blind.

Federal priorities stress the importance of teacher education relating to state and local education authorities. Priorities in the future must stimulate personnel preparation to be innovative and creative in concert with adult services. As a beginning, by having students do practicum hours in adult programs, university personnel can establish mutually beneficial relationships with adult service providers. Consumers who are deaf-blind on our advisory boards are viewed positively by grant readers, but working cooperatively with those who are deaf-blind adults and with adult services is vital.

Conclusion

Personnel preparation in deaf-blind education is related to the other focus areas of this symposium, interwoven with the forces of change in regular education and influenced by the larger societal changes in our country. One does not have to be a visionary to predict that there will be major changes in all personnel preparation in the next decade. We are all part of the future transformations.

I began this paper by taking a retrospective view of personnel preparation in deaf-blind education. Another snapshot of the past shows that 12 years ago 80 experts in the field of deaf-blind education made predictions about the future. They predicted that federal support in deaf-blind education would be decreased and that teacher training would emphasize severe and profound disabilities rather than deaf-blindness (Tweedie & Baud, 1981). These experts' predictions became today's reality.

Let us as a group make positive predictions which pack the power to set direction for the future of personnel preparation in deaf-blind education.

Let us predict that there will be strong and increased federal commitment to deaf-blind education in the next decade. Better personnel preparation programs will result in better qualified teachers who will serve infants, children and young adults who are deaf-blind and their families, and who will be able to meet the challenges of increased interaction with culturally diverse families and the need to work as part of a team with other professionals.

Let us predict that national standards will be established that will provide a high quality blueprint for "best practices." With a clear professional identity, teachers of the future will be able to accept new roles and challenges with support and confidence as societal demands shift and the actual needs of infants, children, and youth who are deaf-blind determine and drive educational services.

Finally, many of the children we serve today will be adults in the next decade. Let us predict that, with collaborative planning, adult and educational services will not be separate systems. Let us predict that they will share the challenges of better serving persons of all ages.

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PERSONNEL PREPARATION: REACTION

Roseanna C. Davidson

Abstract: We must develop a clear, accurate understanding of the population through better exchanges of information about numbers and etiologies. We must also develop as a profession by compiling and publishing our history and establishing a set of standards and a code of ethics. We must make a commitment (and support that commitment with funding) to stable, cooperative pre-service professional training offered at the graduate level in strategic geographic locations. The combination of sensory impairments is the most significant feature to be addressed and calls for professional expertise to make educational and environmental modifications, especially in the area of communication.

Barbara has given us glimpses of the past, present, and future of preparing educational personnel for infants, children and youth who are deaf-blind. I think she has presented a thorough, systematic and organized assessment of personnel preparation, thereby freeing me to present my response in a somewhat more arbitrary fashion. I will submit for your consideration some of Barbara's ideas that I would like to expand on and perhaps a few additional ideas using a *we must* format. At this time I feel like the man who is gripping the gutter of his two-story house while looking down at his little son standing next to the ladder that has slipped to the ground. The little boy calls up to his dad, "Mom wants to know if it's important." I hope you agree with me. It is important!

Areas Requiring Action

In order to prepare personnel for students who are deaf-blind we must do the following:

- Have a clear, accurate understanding of the population.
- Develop as a profession.
- Make a commitment to pre-service professional training.
- Support that commitment with funds.
- Be committed to the idea that it is the combination of sensory impairments that determines the programming needs for students who are deaf-blind.

The Population

We must have a clear, accurate understanding of the parameters of the diverse population of students who are deaf-blind. From this information we can more accurately project the most salient features to include in various types of personnel preparation programs. We have made great strides in the past decade to get a better idea of the number of infants, children, and youth who are deaf-blind, the incidence of deaf-blindness in relationship to the total population of students receiving special education services, and the wide range of etiologies of deaf-blindness. However, through observation of the status of identification and reporting students who are deaf-blind in my own state, reading Dr. Baldwin's annual reports, and through conversations with him, it is clear to me that we have a long way to go. We have to continue to discuss, "What is deaf-blindness?" Some of us may align ourselves with the "orthodox" group, others of us may identify ourselves as members of the "reformed" ideological group. However,

without a clear picture of the current population, we will not be able to refine our notion of deaf-blindness to match the real world. I am aware also that our definition of deaf-blindness determines who is identified and reported on the census. That is all the more reason we need to create opportunities for exchange of information. In Texas, we are beginning a new procedure for identifying and reporting infants, children, and youth who are deaf-blind that will certainly broaden the definition of deaf-blindness in our state. The potential exists to over-identify students. Whatever happens, we must publish and report our results. (Incidentally, I know the journal it will most likely be submitted to, and the professional conference it will be submitted to, I am curious about your recommendations for where such information should go. Where would you expect it? Is there any one place we would all look?)

The Profession

We must develop as a profession. All professions are defined by three features. One of these is a described body of knowledge which includes not only theory and practice, but also the history of the field. Currently we have portions of the history as small chapters in a few books, some of which are out of print, or as copies of transcriptions of speeches that give historical perspective. We need a hardback book that reports the facts, the people, and the sequence of events and practices so that newly trained people have a way to know how we have arrived at this point. This history is the personal experience of many of you who are here today. Your experience is valuable to us. Second and third components of a profession are a set of standards or competencies and a code of ethics. These elements provide a common ground on which to base personnel preparation programs.

Currently, the Council of Exceptional Children - Division on Visual Handicaps (CEC-DVH), the Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER) - Division 3 (Multihandicapped/Deaf-Blind), and the Council on Education of the Deaf (CED) are beginning independent efforts to describe teacher competencies and/or training program standards. Efforts are being made to collaborate on the process. An ad hoc committee made up of representatives of those organizations has been formed, and we will need more professionals to participate in these efforts.

Pre-Service Professional Training

We must make a commitment to pre-service professional training offered at the graduate level. The events of the last 10 years, many of which Barbara described, have left us with the situation of training all individuals on an as-needed basis in an inservice model that cannot provide a broad-based scope of information necessary to develop high quality professionals. There are overlapping theories and practices in each of the following fields: severe disabilities, visual impairments, communication disorders, and deaf education. However, there also exist in these fields distinctly separate applications of some theories and methods and separate goals and methodologies specific to deaf-blindness. We might say that, although regular education acknowledges the individual's need to develop a variety of communication skills, the focus is usually on the refinement of an already reasonably well-functioning communication system. For most individuals who are deaf-blind, however, access to assistance to develop communication of *any* form is essential to enable the person to develop a sense of self, a sense of others, and to have access to information about the world.

There is a need for all types of training alternatives (e.g., pre-service and inservice), using the most viable means (e.g., independent study, videos, or teleconferencing) to efficiently provide access to information. Some types of information are best suited for certain training alternatives. The problem we have had most recently is that we do not have a choice of training alternatives, because our only alternative has been inservice training.

In order to do an adequate job of preparing personnel, I agree with Barbara that we need to develop and maintain professional alliances to support and be supported by. To help clarify the brief comments that I have made, please refer to the following figures.

Funding

We must support the commitment to pre-service training with funds that are, as Barbara articulated, (a) supporting programs in strategic geographic locations; (b) awarded in competitions that are distributed so that programs are not competing with each other; and (c) stable, so that programs have the time to develop, grow, mature, become recognized, and make a contribution. Currently, such grant-funded activities as clearinghouses have such support because it is generally recognized that, in order to benefit the population a clearinghouse is designed to serve, it must have longevity that has been earned by fulfilling its objectives. Programs to train professionals to work with infants, children and youth who are deaf-blind deserve the same kind of support.

Appropriate Programming

We must be committed to the idea that it is the combination of sensory impairments that is the most significant feature to be addressed when assessing and programming for individuals who are deaf-blind. In my observation, many program decisions are based on the individual's functional level without adequate acknowledgement of the need for modifications in activities to accommodate the individual's sensory loss. The younger the child is, the more important it is to provide the optimal level of modifications. There is no excuse for

PRE-SERVICE GRADUATE PROGRAMS TO PREPARE PERSONNEL FOR STUDENTS WHO ARE DEAF-BLIND

FOCUS: SPECIALIZED KNOWLEDGE BASE FOR APPROPRIATELY SERVING STUDENTS WHO ARE DEAF-BLIND

- teacher training
- consultant preparation
- integration of knowledge, practice skills and values
- ongoing scholarly activity to support and enhance the field of knowledge with an emphasis on research

INSERVICE PROGRAMS TO PREPARE PERSONNEL FOR STUDENTS WHO ARE DEAF-BLIND

FOCUS: NEW DEVELOPMENTS IN KNOWLEDGE AND SKILLS AND THE IDENTIFIED NEEDS OF PARTICIPANTS

- Supplement knowledge and skills of trained teachers
- Supplement knowledge and skills of consultants
- Supplement knowledge and skills of ancillary staff and related services professionals who work with students who are deaf-blind
- Supplement knowledge and skills of teachers of students who are deaf-blind who have not had pre-service training
- Provide training to families
- Report successful practices and research

accepting the argument that the child's level of sensory functioning is adequate for his cognitive ability. When we do that with very young children, we have determined that the child's functional ability will not change. Children learn about their world through their senses. If we do not adequately intervene, the child will have severely restricted learning alternatives.

A functional, totally inclusionary, community-based instructional program is not meaningful to a child who is deaf-blind if appropriate program modifications are not made. Foremost, the specifically identified communication mode that a child uses must be infused into all activities or else the child will have a lifetime of "Weekend at Bernie's" experiences. Let me explain. *Weekend at Bernie's* is a movie whose main character is a dead man who is included in all of the activities that he had scheduled before he was murdered. Bernie's friends help him host a cocktail party where he drinks and is included in conversations. Bernie also sunbathes and naps by the pool and goes water skiing with his friends. Are our children who are deaf-blind to be treated as Bernie?

It is a Bernie experience if a child who is deaf-blind is left positioned so that he can touch a switch that will activate a dancing bear which the child cannot see or hear.

It is a Bernie experience if a child who is deaf-blind is scheduled to watch Disney movies on Friday afternoons with all the other children in their building who have earned a reward.

It is a Bernie experience when a child waits an hour in order to partially participate in a science activity with her peers.

Children who are deaf-blind do not have time to waste waiting to participate. They must spend their time doing activities that are meaningful to them (not meaningful to teachers or peers). All of the Bernie experiences I have described can be turned into meaningful experiences with the help of a knowledgeable, flexible professional in deaf-blindness.

To include individuals who are deaf-blind in meaningful ways, all activities must be modified to ensure that

- the child knows or has the opportunity to know what is going to happen.
- the child can develop a sense of power over the world.
- the child can know about the world.

We must have trained educators who understand the unique needs of a wide variety of students who are deaf-blind, now that our educational system has included everyone in all regular educational options. We must have professionals who can identify educational and environmental modifications that are necessary for each child. We must have professionals who advocate for better quality of life for persons who are deaf-blind.

Summary

I have mentioned several ideas that I feel we must take action on to accomplish. We must have the help of the Office of Special Education and Rehabilitation to accomplish the development of stable, supported pre-service training programs. As a body of professionals, we have to take the steps necessary to develop the profession further. The profession exists and is real to us because of the time, effort, dedication, and love we have put into working with individuals who are deaf-blind. The profession is real because we have made it real, just as in the story of the *Velveteen*

Rabbit, the boy made his stuffed rabbit real because of his caring and attention. The rabbit was real, but at first only the rabbit and the boy knew it. Then the nursery fairy came along and made the velveteen rabbit into a *real* rabbit that everybody could see.

We need to take the steps necessary to make the profession *real* for people outside our association. Being committed to understanding the impact of reduced sensory ability in the two distance senses, working to clarify our understanding of the population, and supporting pre-service graduate training of professionals will greatly enhance the visibility of the profession. We can be *real* for all the world to see.

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EDUCATIONAL SERVICES: PRESENTATION

Michael T. Collins

Abstract: The National Association of State Boards of Education stated in 1992 that children classified as special education students are not achieving what they are capable of; they are not being prepared for life after school; and current mainstreaming practices are not producing their intended outcomes. Many of these problems are due to a rapid shift into decentralized services without a reasonable infrastructure in place to assist the local school systems. We must do the following: Establish a national clearinghouse with a newsletter and resource referral system; set up more meetings and training activities across state lines to ensure a fertile exchange of information; fund development of high quality training materials; fund 8-10 personnel preparation programs within universities that are in strategic geographic locations; conduct research on what methods and services work; develop within each state a network of consultant/itinerant/resource people; utilize more paraprofessionals (similar to Canada's intervener program); develop a "quality indicators" assessment; and finally, set up an advisory committee made up of consumers and professionals in the field.

Introduction

I must admit that it is with considerable trepidation that I follow all the distinguished speakers who have preceded me. How does one follow such an impressive group and have anything left to say? It is worse yet to look at the bright people following me, who have the opportunity to contradict me.

Nonetheless, I am pleased to be here to participate in this symposium, and to assist in the setting of priorities for the future. This was last done by OSERS (Office of Special Education and Rehabilitative Services) in 1978, so it is safe to say that a meeting to revisit federal priorities is somewhat overdue.

As we examine the priorities for OSERS to consider in the next decade, it is perhaps wise to view the educational priorities (a) in the context of the recent history of the education of children who are deaf-blind in our country and (b) in the context of today's approaches to the education of disabled children and youth. So let us first examine our past, and then we will shift our focus to the present.

Recent History

The past two decades have seen some interesting changes in our service delivery to people who are deaf-blind. In the 70s we witnessed the creation and development of a network of multi-state regional centers for children who are deaf-blind. While they varied in number and composition over time, these centers provided a national network of communication and sharing for those serving children. They tended to be staffed by personnel who had specific training related to people who are deaf-blind, and their staff provided ongoing training and consultation to local programs and produced many publications and training videos which were nationally available.

Most important, the regional centers had the responsibility to develop direct service programs for children who are deaf-blind, prior to the enactment of mandatory education legislation. As a result, in a very short time, from about 1970 to 1975, most states had developed several specialized programs for children who are deaf-blind, within residential schools, state institutions for the retarded (as they were then known),

and many public schools (Dantona, 1974). Many "deaf-blind programs" resulted, frequently, as many as four to eight within a given state. Some of our bigger states, like California and Texas, had classrooms for children who are deaf-blind scattered all over the state, within some of their major school systems. A typical state would have a large residential program at the school for the blind, one or two large residential programs within state schools for the retarded, and several small public school classes for six to eight children.

However, it must be noted that, measured against today's standards, virtually all these programs were either in segregated settings or were mostly segregated classes within a public school setting. Another shortcoming was that not all children within the state were served by these specialized programs. In the days prior to P.L. 94-142, these programs could be selective about admissions, and were in fact so. Children not admitted into these classes were either served in other generic programs for children with varied disabilities or were not in an educational program at all. The personnel within regional centers had a responsibility to support, develop and advise the specialized programs for children who are deaf-blind within their region, but they also had a very large consultative caseload of children who were in no specialized service.

It must also be noted that, during this decade, funding was relatively available and adequate. The $16 million appropriation for Centers and Services to Deaf-Blind Children went a long way toward ensuring that direct services were established and that staff training activities were routinely provided. Federal funding covered over half of the cost of direct service programs in most states, and this healthy federal appropriation was even adequate enough to ensure the continuation of these programs during the recession of the 70s.

Another significant characteristic of this decade was the establishment of several university programs to prepare personnel. Programs to train teachers were initiated at Boston College, San Francisco State University, Peabody College, Portland State University, Michigan State University, the University of Pittsburgh, Ohio State University, Cal State L.A., Florida State University, the University of Alabama at Birmingham, and others, mostly with federal support (Campbell, 1976). Ponder for a minute the number and geographic dispersion of these programs. We were educating over 100 teachers annually who had specific training. Through the regional centers, the graduates of these programs were readily placed in positions throughout the nation, teaching children who were deaf-blind.

Let us acknowledge that the proliferation of these programs was again directly relative to the healthy funding levels being approved for such training and due to the internal advocacy of Josephine Taylor within the Bureau of Education for the Handicapped. Nonetheless, some regions of the country, notably the Midwest and rural West, had a very inadequate supply of teachers.

During this era, not only was the supply of teachers better than now, but these teachers, when graduated, actually had jobs to go to which were related to their training. A trained teacher could get a job teaching children who were deaf-blind in any state in the nation. In addition, with some experience, they were able to fill the many specialist positions within regional centers, state departments of education, and universities. We had a pool of people from which to recruit our future leaders. Consequently, many of our states had personnel in leadership positions who had

both training and direct teaching experience with the population (Campbell, 1976).

It is also noteworthy that teachers, staff, and parents of children who were deaf-blind were well informed about the purposes of the federal program and the state and multi-state programs under Section 307.11. This was, of course, due in part to the centralization of services, but did result in a level of accountability within these organizations.

What was instruction like during these years? Well, it should first be noted that many children were taught in self-contained classes of children who were deaf-blind, with four to six children being taught by a teacher and several aides. Instruction therefore tended to be carried out in classes with very low staff-student ratios. Frequently the teacher had specific training in either teaching children who were deaf-blind or children with multiple sensory impairments. When such training was lacking, the teacher knew nonetheless that he or she had accepted assignment to a class of children who were deaf-blind, and therefore the teacher participated in all possible training activities, read about the instructional techniques used with the population, and gradually acquired useful teaching skills.

Instruction tended in many programs to be very developmental, with a focus upon academic or "pre-academic" teaching. The teaching of language skills, cognitive skills, reading, writing, math, and sensory development prevailed, and in many schools the teaching of these was very good. Teachers knew how to check the child's hearing aid, knew several possible language modes and how to teach them, could teach braille when needed, could carry out auditory training, utilized appropriate assessment tools, implemented curricula to stimulate the use of residual vision, and had the ability to teach children to use these skills in everyday life situations. The teaching of daily living skills was usually well integrated into the curriculum.

In some places the academic content was over emphasized to the neglect of functional curricula; while some basic daily living skills were taught, too often other practical, applied skills were lacking. Frequently, the activities were not terribly age appropriate, with adolescents required to engage in very juvenile activities. Elements of choice-making and self-determination were frequently lacking from the curricula. Vocational training was either nonexistent in some schools or, in others, was oriented toward preparation for sheltered work. In short, much of what became state-of-the-art instruction in the 80s (Snell, 1987) was typically not addressed.

The Current Status of Educational Services

It has been suggested that we should incorporate into our papers some reference to how educating children who are deaf-blind fits into the context of other regular and special education trends which are prevailing in today's society. It is first essential to note that our entire philosophy of education of children with disabilities has shifted in several ways since the 1970s. We have moved from conducting education solely in segregated facilities to offering more services integrated into the local community. We have moved from centralizing our service offerings to decentralizing them, so as to make them available in every child's community. Functional curriculum which is age appropriate has replaced a lot of academic teaching. Vocational training and placement is now regarded as a key aspect of school curriculum. We have shifted from offering

services, which were highly specialized to the child's specific disabilities, to offering a curriculum which is more "generic," being generalized to all children. In this paper, I am not placing a value on these trends; I merely wish for us to acknowledge them as existing and influencing how children currently receive services.

A recent study of the Federal Resource Center at the University of Kentucky analyzed current issues and trends within special education, in an attempt to predict the future. While some of the predictions in this study sound a bit like a summary of past practices, a few general trends are interesting to note since they have implications for the education of children who are deaf-blind. To quote, "There will be a critical shortage of special education personnel at all levels. In an effort to deal with these personnel shortages, paraprofessionals will have an increasingly important role in service delivery and will provide more direct instruction" (Hales & Carlson, 1992, p. 5). (This prediction raises a question regarding children who are deaf-blind: Who will supervise, monitor and refine the work of these paraprofessionals?) "Also, in an effort to meet the need for services, regular educators will be trained and acquire the skills necessary to serve children with mild disabilities thus blurring the borderline between special and regular education" (p. 5). (What people at the local level have the ability to train these regular educators within most communities? Who can train them?) "States will cut special education funding as more students are served in regular education" (p. 6). (If so, how can we ensure that our students get the resources they need, rather than having special education funding support the football team?)

It has been suggested that perhaps I could tie into this presentation the ways in which America 2000 might have a bearing upon education of children who are deaf-blind. I am not sure this is possible. The America 2000 goals were formulated for the general student population without much regard for how they might apply to special populations (Mecklenberger, 1992). Therefore, they are largely irrelevant; when one considers the major changes which schools must implement to make education more appropriate for children who are deaf-blind, the America 2000 goals miss the boat. I would suggest that they are an outstanding example of how inclusion might go awry: We have written goals for the general population without regard for how they might need to be individualized to different populations.

These general trends in special education have had some tremendous impact on how children who are deaf-blind are educated. The typical scenario today is that the child is taught in his home community; his classmates are other children with multiple impairments, or with no impairments; his teacher has no specific training in deaf-blindness; if he is fortunate, a trained person may consult with the classroom monthly or annually; his classes focus on many functional skills, but are weak in academic teaching, sensory development and language skills; as he approaches adolescence, he probably has a reasonable program of vocational training, depending upon the community in which he resides; and his parents may not know what to do with him at home, or they may be in need of a knowledgeable person to advise them.

We must acknowledge that we have a fairly strong level of technical assistance being provided through our national program for children who are deaf-blind. Within each state, the single and multi-state centers for children who are deaf-blind have primarily a technical assistance role. The technical

assistance project called TRACES (Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments), operated by Teaching Research in Oregon, has been a fine support to all states as they attempt to upgrade their services to children who are deaf-blind. Likewise, the Helen Keller National Center's Technical Assistance Center fulfills a similar function for transition-aged students. Both of these projects sponsor training nationally, and publish newsletters with good information for the field. Similarly, the American Foundation for the Blind's project to provide training tapes and learning modules in communication and mobility will be a wonderful resource for all of us who have the job of providing basic training on an ongoing basis. We also now have a national information center and clearinghouse (DB-LINK: The National Information Clearinghouse on Children Who Are Deaf-Blind) being developed by Teaching Research and other organizations, including ourselves at Perkins, so that the important literature and resources will be catalogued and easily accessible to all.

Thanks to the enactment of P.L. 94-142, we live now in an era when all children receive educational services. Due to P.L. 94-457, most infants and toddlers will also be receiving the educational headstart which they require. No longer will we have to see children who are deaf-blind sitting at home uneducated due to distance, funding shortages, or rejection.

The federal legislation has also brought about a philosophical and practical shift toward mainstreaming and toward the full inclusion of all children in their neighborhood schools. Most children and their families now have at least the option of an education in their neighborhood schools. With increasing frequency, this education typically includes at least some partial integration with nondisabled peers.

The integration movement has definitely resulted in a much greater *dispersion* of children who are deaf-blind. While they used to be served in more concentrated pockets, due to the greater abundance of specialized programs, they are now served in a much greater number of schools, spread over a much larger geographic area. You can see a graphic display of this phenomenon on the overheads: the first shows the location of the 215 children who are deaf-blind in New England in 1982, served in a total of 29 school buildings; the second shows our current population of 267 children in 1992, served in 218 different programs or sites. This same phenomenon repeats itself in every state and region in the nation. Infrequently, does one find two children who are deaf-blind served within the same building, let alone the same classroom.

As you might imagine, the population dispersion makes the state coordinator or consultant's job a much more challenging one. How does a consultant/specialist adequately assist and support programs for 185 children who are in 138 different schools in the state? These 138 schools definitely require a greater level of such assistance than in the past, since they do not typically employ specialists for children who are deaf-blind. With only one or two children per building, or often per district, they cannot possibly afford such a low-incidence specialist. Nonetheless, in comparison to past decades, we have a greatly increased number of special educators and general educators who need some basic training in instruction of the children who are deaf-blind.

The forementioned factors result in most states repeating training, again and again, in the very elementary instructional strategies

known to be effective with children who are deaf-blind, for an ever-changing body of learners. The result is that very few educators are accumulating the larger body of knowledge which they need in order to conduct sound educational planning for the children.

If we had personnel shortages in the past two decades, they are now increased ten-fold. Only three or four universities nationally now receive federal support for pre-service programs to train teachers of children who are deaf-blind. They are training no more than 20 or so teachers annually. Many other universities offer programs in severe disabilities, but there is great variation in the extent to which they address sensory losses, and, too frequently, people who are deaf-blind receive only cursory attention via survey courses which provide an overview of a multiplicity of disabilities. Please recall that this is occurring in an era when the need for such trained teachers is at an all-time high, since children are served in such a great *number* of places. Local school systems, which, with increasing frequency, have the mandate to educate the child, must proceed without personnel with the expertise to train and support their teaching staff. For this reason, the Hilton/Perkins National Program has chosen to use much of the funding from the Conrad N. Hilton Foundation to support graduate degree training and/or certification coursework for over 100 teachers annually within six universities.

Another phenomenon worthy of mention is that, with children spread out so far over such a large number of districts, there are very few jobs available for a trained teacher of children who are deaf-blind. School systems are not allocating a specialist position for one or two children in each district, and graduates therefore have to search broadly for jobs in which their specialist background can have broad impact for numbers of children. The expertise of the specialists is broadly needed, but positions which make use of their skills are few and far between.

Given that we have such a severe shortage of adequately trained teachers, we likewise have a greatly reduced pool of people from which to appoint consultants, specialists, and resource people. Where are our future leaders to come from? Even when a school system has the funding for a resource specialist, they have difficulty finding appropriately trained candidates. More than 75% of the positions for state consultants, or coordinators of the state and multi-state programs under Section 307.11 (formerly Title VI-C) are filled by people who have neither training nor direct teaching experience with the population. Yet these are the same folks who are expected to be our resource people, to train the local schools to offer appropriate instructional content to the child who is deaf-blind. Even our national technical assistance projects and programs, such as TRACES, the Helen Keller's Technical Assistance Center, and the American Foundation for the Blind, have increasingly had difficulty recruiting trained personnel when vacancies occur or new projects are begun.

The current era is also one in which funding is less than adequate and definitely harder to access. The federal Section 307.11 program currently allocates $12.8 million for services nationally. This obviously buys far less service at today's costs than could be purchased for $16 million in the early 1970s. Due to inadequate appropriations and the ideals of the "new federalism" in which it is affirmed that states should be responsible for most of the cost of direct services, the Section 307.11 program has evolved into almost exclusively a technical assistance program. The same factors have resulted in

fewer federally supported personnel preparation programs. I want to say something loud and clear regarding this recent concept of federal responsibility: When it comes to services to low-incidence populations like people who are deaf-blind, *the new federalism doesn't work!* If we think that states are going to recognize the particular needs of such a small population, and develop appropriate services to meet their expensive needs without federal support, we are kidding ourselves. It has not happened in the past and will not happen in the future. Our population will become lost in the larger masses being served; this phenomenon is already becoming evident.

It has recently become obvious to me that we are having some continuing difficulties in agreeing how to identify the population across the nation. The incidence of deaf-blindness ranges from under 1:1,000 to 3.7:1,000 (deaf-blind:special education children) depending upon which state is doing the counting. This is an especially crucial problem to resolve in that the distribution of funding is directly tied to the child count. Therefore, states which have historically done a poor job of finding their children get less funding, while states who add children to the registry without scrutiny or conscience get more funding. This unfortunate occurrence causes states to compete jealously against one another and encourages states to inflate their identified populations far past the point of being able to serve them. While many states have greatly underestimated their population on children who are deaf-blind, in the national child count (Baldwin, 1992), others are greatly overstating their population. This seems without purpose unless there can be some considerable financial or programmatic assistance ensuing.

A good summary of our present shortcomings is found in the words of Dr. Robert M. Davila. In addressing the meeting of project directors in October of 1990, he said, "This philosophy, which has at its heart the full participation of individuals with disabilities in every aspect of community life, has, in some ways, outstripped our present ability to make the philosophy a reality for all whom it embraces . . . . Although we in OSERS embrace the concept of full inclusion, we also believe that our philosophy outstrips our present capacity to achieve it fully" (p. 2). He goes on to cite the national longitudinal study on transition conducted by Stanford University, which shows about 33% of mainstreamed students failing one or more classes and 10.5% failing six or more classes (Davila, 1990).

Likewise, a recent Policy Guidance issued by OSERS cautions schools that the least restrictive environment (LRE) for a child who is deaf may not be the regular classroom. Because of the "inherently isolating" nature of deafness and the special problems children who are deaf have in acquiring language skills, "effective methods of instruction that can be implemented in a variety of educational settings are still not available," OSERS says. The notice goes on to say that "this lack of knowledge and skills in our educational system contributes to the already substantial barriers to students who are deaf in receiving appropriate educational services . . . Any setting, including a regular classroom, that prevents a child who is deaf from receiving an appropriate education that meets his or her needs, including communication needs, is not the LRE for that individual child" (Federal Register, 1992, p. 49274-76). If true for children who are deaf, do not these principles apply even more so to the child who has both a hearing and a vision loss?

A recent report, issued on October 23, 1992, by the National Association of State Boards

of Education, calls for an inclusive system of education that applies state goals for achievement and outcomes to all students, including those with disabilities. It says that, time and again, the study group was forced to answer "No!" to the following questions:

- Are children currently classified as special education students achieving what they are capable of?
- Are they being prepared for life after school?
- Are current mainstreaming practices producing their intended outcomes? (National Association of State Boards of Education, 1992)

In short, the study is an indictment of both our past practices of segregated education and our present poor attempts at inclusion.

In reflection, I observe that we have bought into a philosophy of integration and service at the local level without any attempt to build an infrastructure and support system to make it work. In stating this, I am not arguing that the philosophy is erroneous or misplaced. Certainly participation in one's family and community are values which we all hold dear for children who are deaf-blind, as for all children. Nonetheless, we must recognize that, at the local level, thousands of children who are deaf-blind are underserved or inappropriately served, for want of any local expertise about the population. Certainly, some local schools employ staff with such knowledge, or staff who have the initiative to find out what they need to know to teach a child. But too often the child's needs are simply not recognized, let alone addressed in the Individualized Education Plan (IEP).

Minimum Educational Requirements

I suggest that children who are deaf-blind typically require certain educational content within their IEP, if their education is to be appropriate. Obviously, children who are deaf-blind, like all severely disabled children, need functional curricula, age-appropriate activities, vocational training, social interaction with peers (disabled and nondisabled), and so on. However, an educational plan for a child who is deaf-blind must minimally incorporate some other things which must be addressed vis-a-vis the disabling conditions, including the following:

Language goals in the child's most useful modalities, written at the child's current language level.

Sensory development activities. These would typically include auditory training following an established developmental sequence, and, in the case of partially sighted children, low vision stimulation activities, which also follow a developmental sequence.

Teaching strategies which incorporate the child's most likely learning styles, as determined by appropriate assessment strategies. It is essential to know with what kind of instructional ratio the child learns best; how the child copes with distracting environments; where materials are best placed for the child to attend to them; the size, shape, and color of materials which the child can see; how structured the environment and teaching day must be for the child to make sense of his world; ecologically, what things in the child's environment promote versus impede learning; and so forth.

Mobility training. This will ensure the person's ability to explore and interact with the environment, to the maximum extent possible for that individual.

Expanding the student's cognitive skills. The curriculum should accommodate the fact that they cannot observe this world very well. To illustrate this point, such adaptations may include (but certainly are not limited to) more tactile explorations opportunities, more use of models and real objects to explain concepts, more reliance upon field trips and actual experiences as opposed to class discussion, more preparation of descriptive information to allow for the student being unable to see instructional materials, and more individual interpreting of the events occurring in the classroom and the environment at large. The young child who is deaf-blind needs specific instruction in the use of objects and their various functions, gradually expanding the child's use of objects through incremental instruction (à la Piaget). These concepts need to be specifically taught, because the child who is deaf-blind often cannot observe how others in the environment make use of objects (Enright, 1977).

Assessing the child's present capabilities for social interaction and creating situations which ensure the opportunity for such interactions to occur. Often the child who is deaf-blind needs to be specifically taught social behavior, from the earliest acceptances of others into his life space to relating to others through language, playing of games with others, and taking turns. Again, if the child who is deaf-blind does not witness the social interactions of others, he has no model for this kind of behavior to occur spontaneously and therefore often needs specific teaching to acquire such skills. Obviously, for students with a developed language system, it is important for social interactions to be in the child's primary language mode if they are to be "quality" interactions from which the student who is deaf-blind might benefit, and if progress in social development is to be achieved.

Regardless of functioning level, any student who can benefit significantly from currently available educational technology must have access to it and must have appropriate instruction in its use. This is true whether we are talking about a head-switch for a child with severe cerebral palsy or print-to-braille computer software for the mainstreamed student.

Additional Requirements

In addition to the above factors, for students who have the academic capability, there are some other curriculum considerations if an educational program is to be judged appropriate. First, students must have the opportunity to learn to read and write. That is to say, students with the ability to learn it have a right to be literate, and we have the obligation to teach them. Whether this capability can be achieved through print or whether the child can only learn to read through braille, if they can be literate, they must be. Likewise, if the student is able to follow a reasonably "normal" sequence of courses and earn a high school diploma, he or she must be afforded this opportunity. To "track" students who have the ability to earn a diploma into a "special certificate" track, only because we don't know how to adapt the curriculum for them, is doing them an injustice.

All of the above also presumes an ability on the part of the school district to conduct a reasonably accurate assessment of the child's needs at present and to arrive at some likely educational expectations.

I submit that, all too often, the above specific content needed by the child who is deaf-blind, is altogether lacking. This is frequently true both in full inclusion programs as well as in some of the segregated classes for severely disabled children, in which children who are deaf-blind happen to be served. Sometimes a

specialist in one of the senses (teacher of the hearing impaired or visually impaired) or a resource person in moderate or severe special needs will consult to the classroom on a regular basis. However, far too often, this is not a person with real expertise at assessing the child's needs and offering a curriculum which incorporates the above factors. The result is that the child receives a program which is only partially appropriate. Some of the above needs get addressed in the IEP and others are overlooked, based on the expertise of the people at hand.

Sometimes, not only does the district lack this expertise, but there is also nobody to call upon from the county, the intermediate school system, or the state. Therefore, the consultative input which is provided is also addressing only a part of the child's needs. A comparable lack of expertise on the part of the resource people in the state will produce the same gaps in the appropriateness of the student's plan.

This situation is not acceptable. We cannot continue pretending that a system with such large gaps is a functional system. We will never improve the quality of what children who are deaf-blind receive at the local level unless we all acknowledge that significant improvements are needed. This acknowledgement must be made at every level, from the U.S. Department of Education down to the newly hired teacher aide who has been assigned to a child who is deaf-blind for the first time.

A Brighter Future

Action Steps for OSERS

Many of the problems which we are experiencing in education of children who are deaf-blind today have evolved due to a rapid shift into a decentralization of services without a reasonable infrastructure in place to assist the local school systems in developing good programs for children. This does not mean that the problems are unresolvable or overwhelming; we simply need to apply some good thinking to develop some likely solutions. What I hope to share is a *vision* of where we might be headed, and some actions which OSERS might consider taking to improve services. Let us first turn our attention to some of the general directions which OSERS might consider to help services nationally, and then look at some specific actions which we as professionals in the field must take to improve matters.

1. We need first to **reestablish a National Network in Deaf-Blindness**, similar to what existed in the 1970s. OSERS has recently awarded a grant for the operation of a national clearinghouse on children who are deaf-blind. We desperately need the national organizations, such as TRACES, the Technical Assistance Center of the Helen Keller National Center, the American Foundation for the Blind, the Hilton/Perkins National Program, and each state's rehabilitation and Section 307.11 projects, to pull together toward common ends to develop the clearinghouse, which helps the field build this national network. A strong national newsletter and resource referral system can become a pivotal point in our relationships across state boundaries. The national clearinghouse must become a vehicle by which professionals, parents, and consumers can be linked together, informed of each other's efforts, updated about literature in the field, and galvanized to act in mutual support. The clearinghouse will need more Section 307.11 funding to become the national resource which the field needs.

2. We need more frequent **meetings and training activities which cross over state lines**, to ensure a fertile exchange of information in our field, and to avoid costly duplication of efforts. We need continued national conferences, meetings, and symposia, like this event, which bring us together as a community of individuals with common interests. OSERS might sponsor more events like this meeting and reward proposals from states which propose joint activities with neighboring states in order to encourage a more fertile field. No collection of people can consider themselves a professional community unless they are continually visible to each other as a community.

3. We also need more projects funded to develop high quality training videotapes and learning modules. Those who provide training to staff desperately need **a variety of high quality training materials** to enhance the training. I hope the future will see several such training modules developed by a variety of organizations and used in a myriad of ways, but especially to augment "in-person" training. I would especially suggest more requests for proposals for development of training materials which are a little more modest in scope and content than what has been required under the present grant to the American Foundation for the Blind. As a result, more such products may be developed.

4. To have an adequate supply of specialists, we need at least 8 to 10 **strategically located programs of personnel preparation** within our universities, which are training people to assume positions in both education and rehabilitation. These programs need to be funded for a longer term than a three-year federal grant, and they should be expected to develop into true "Centers of Excellence." I envision such universities not only preparing more personnel, but also conducting inservice training and summer programs, carrying out research, developing training materials, and providing direct technical assistance through evaluating children who are deaf-blind and advocating that their services be improved. Such centers could be firmly rooted in reality via strong, collaborative ties to direct service programs or Section 307.11 programs in their respective regions of the nation. I also envision them strongly linked to one another, to create a national standard of adequate personnel preparation. The training of teachers of children who are deaf-blind has not been a high priority of the federal government for several years. The persons responsible for the Section 307.11 program must convince higher authorities within OSERS to require the Personnel Preparation Division to train more specialists.

5. I suggest that we need some honest, objective **research on what methods and services work** for people who are deaf-blind. We need no more esoteric or nongeneralizable studies on how to teach four words to a child who is deaf-blind via behavior modification, the benefits of sitting in the same lunchroom as nondisabled peers, or how many people who are deaf-blind one can fit on the head of a pin. The questions we need to answer are easy to identify: What instruction is most essential to ensure growth and development? What services to the child make integrated programs work? What makes them fail? Under what conditions is an integrated setting more limiting than enabling? Under what conditions is a segregated setting necessary or inappropriate? What are the best training systems to ensure that the large numbers of general and special educators know what they are doing with these children? In other words, let's conduct some research which answers the real questions without bias and without the fear that our philosophies and

beliefs might be shaken by the answers. In order for the Section 307.11 funds to go further in their impact, I suggest that perhaps a committee of OSEP staff and Section 307.11 personnel could suggest to the National Institute on Disability Research and Rehabilitation (NIDDR) some specific research needs, the topics of which are "field-initiated."

6. To improve services at the local level, we must develop within each state **a new network of consultant/itinerant/resource people**. At the intrastate level we need such people within each region, employed by the state or by intermediate educational units or collaborative districts. These positions must be filled by specialists, with specific training related to children who are deaf-blind. Their responsibilities should include assistance in program development for individuals and ongoing consultation to all districts within their region. For years, such specialists have been employed in the areas of vision impairment or hearing impairment. Yet, in spite of lack of local expertise, such positions have rarely existed. In short, we need development of a number of jobs and a cadre of personnel who have not existed to this point. I would suggest that this is the only means by which we can pull ourselves out of the continuing downward spiral of having to provide basic training to an ever-changing body of people. A strategy for developing such a group of specialists and creating jobs for them should be a required part of every state's Section 307.11 plan. Some models of what such a plan might look like could be suggested by OSERS to help states understand the concept.

7. If the above cadre of specialists were created, we might benefit from utilizing **more paraprofessionals**, under a model similar to Canada's intervener program. An intervener for each student at the local level could work under the direction of the specialists who periodically consult to the classroom staff. Interveners could have ongoing training from the specialists, very specific to the individual child's needs. This would increase the likelihood of success in inclusion programs, and allow us to stretch our masters-level specialists further.

8. An inter-agency team of professionals should be funded to **develop a "quality indicators" assessment** which states, school districts and parents can use to determine whether the *content* that is being taught meets a standard of good practice for the teaching of children who are deaf-blind.

To accomplish the systems change that is needed, we obviously need a greatly improved federal program—one which exceeds by far our present capabilities. We need funding beyond our present levels, which means that we must do a lot of work *together* to influence our appropriations committees.

9. Many of the changes I am suggesting require a fresh look at the national program's purposes and activities. In addition, we must find a way for OSERS to receive input on needs from all of you who work at the grass roots level, including teachers, counselors, parents, and consumers. The perspectives on the needs of the population must be shaped by those who work directly with people, and not only those employed in universities or "grant factories." It is beyond my understanding why a national program to benefit a specific population does not have **an advisory committee made up of consumers and professionals in the field**.

Action Steps for Ourselves

In addition to altering the practical means by which services are delivered and personnel are trained, we must also amend our philosophical orientations. There are several

issues of a philosophical nature which I believe we must confront within ourselves if the future is to be an improvement upon the present.

1. First, I remind you that current educational philosophy within our field is moving away from specialized services toward more generic services. We must stand firm in our refusal to accept generic vanilla for a population whose needs call for Howard Johnson's 28 flavors. An endorsement of generic services is an endorsement of the current inadequacies in our system, and silence is always an endorsement.

2. We in special education have a "bandwagon" mentality to our prevailing philosophies. Just consider the buzzwords of the past couple of decades: task analysis, behavior modification, patterning, sensory integration therapy, coactive movement, vestibular stimulation, least restrictive environment, age-appropriate, ecological, mainstreamed, non-aversive treatment, integration, assisted (facilitated) communication, and full inclusion. Our tendency is to jump on the bandwagon of the latest buzzwords, and act as though everything we knew previously is obsolete and irrelevant. A scientific body of knowledge does not accumulate in this manner, and neither does a sound educational philosophy.

3. We must draw upon the strength of our convictions, to advocate for what is right for children and adults who are deaf-blind. In the past, when prevailing educational philosophies or administrative priorities were resulting in harmful results for our populations, we have been less than outspoken about these effects. We must not hesitate to point out inadequacies in services when we see them. We must help when we know what is needed and admit it when we do not know. We must insist upon the level of specialization which this population requires, because nobody else will. We must serve as advocates for the population and be willing to go to hearing or to court to defend what people who are deaf-blind need.

4. We must start to focus more upon the quality of the instructional and programmatic content which people who are deaf-blind are receiving, and we must focus less upon the place in which the person is served. The quality of services is determined by many indicators, of which the number of nondisabled peers in the environment is only one. Permit me to deviate for a moment to quote F. Scott Fitzgerald: "The mark of a truly first-rate intelligence is the ability to hold two opposed ideas in mind at the same time and still maintain the ability to function." We must begin to integrate our ideas about the benefits of integration and the benefits of knowledgeable expertise. We have acted as though these two ideas are diametrically opposed when, in fact, specialization should be able to happen quite nicely in all settings. We have argued excessively about *where* children should be served; we have not focused enough upon *what* they should be receiving.

These times of change in service delivery have been turbulent times. We are all a bit insecure about our values and priorities for services to the people who are deaf-blind. To borrow the words of Dr. Davila again, "I foresee a time when we will look back to the 1990's, to our frustrations, our growth, our change, our successes and failures, and we will see them as steps in a long, often painful, but ultimately worthwhile process" (Davila, 1990, p. 2). I hope that we will also look back on these days of change and be proud that we insisted upon a consistently high standard of education for children who are deaf-blind throughout and in spite of our own changes and evolutions.

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EDUCATIONAL SERVICES: REACTION

John M. McInnes

Abstract: In the province of Ontario, Canada, a program to provide services to children who are congenitally and early adventitiously deaf-blind had the following goals: to educate and advise parents and siblings how best to deal with the child; to support the classroom teacher so he or she could provide day-to-day support; to work with therapists and other professionals to educate them; and to provide information to members of the medical profession. Specially trained consultants worked with both parents and teachers to develop a program designed to meet the needs of each child, to be delivered in the home, the community, and the school. A fundamental and very successful aspect of the overall program was the use of trained local individuals (interveners) who provided the support necessary to allow the child to function successfully in the least restrictive environment.

I wish to thank the planning committee for this opportunity to share with you some thoughts concerning the points that Mr. Collins has raised in his paper. My initial response after reading his paper, three weeks ago, was that Mr. Collins had done an outstanding job of reviewing the history of services for those who are deafblind. His observation of the present state of affairs of services for those who are deafblind completely parallel those which I have had the opportunity to form during visits to various parts of the United States, and his "blueprint" for future directions leaves little to be desired. In short, my first response to the paper was, "Well done!" I can only echo and reinforce the points he has made.

It is now generally accepted worldwide that deafblindness is a unique disability. In addition, it is gradually being recognized that the label of "deafblindness" covers two different disabling conditions. These are not blindness and deafness but rather congenital and early adventitious deafblindness, and later adventitious deafblindness.

Moreover, those of us who have had the opportunity to work over the last 25 years with those who are congenitally and early adventitiously deafblind and watch them grow, develop, and exceed our expectations at every step, have reached another milestone in understanding. Those who are congenitally and early adventitiously deafblind do not become later adventitiously deafblind when they leave school. Programs and support services designed to meet the needs of the adult who is later adventitiously deafblind will not meet the needs of those who are congenitally and early adventitiously deafblind when they become adults.

Partly because of a problem caused by compartmentalization into preschool, school-age, and postschool services, and partly because we in services for those who are deafblind adopted our definition of success from programs designed to support other disabling conditions, we have tended to equate success with independence. We have also adopted a definition of independence to mean "to function without the help of another person." Put another way, we have defined the successful program as one from which the person who is deafblind will graduate, being able to function as though he or she were a nondisabled person or a person who is later adventitiously deafblind.

Defining the Disability

In the most recent world conference held at Orebro, Sweden in July 1990, one of the most elegant and significant ways of encapsulating the whole question of deafblindness was made in a motion, which was unanimously passed by representatives of nearly 50 countries, which changed the spelling of "deaf-blind" to one word: "deafblind." If you think about this you will quickly see that it says in one stroke everything that needs to be said about deafblindness as a unique disability.

Strangely enough, after 25 years, the question I am most asked when working as a consultant in various areas both in United States and in Canada, is, "Who should be treated as deafblind?" We have definitions, but definitions do not answer the questions of the administrators who are responsible for paying for these services. Meshcheryakov in the excellent book, *Awakening To Life*, addresses the problem. He points out, "Deaf-blindness is [usually] defined as the loss of sight and hearing from birth or early infancy and dumbness resulting from lack of hearing." He states, "The definition is inadequate. The definition of deaf-blindness from the pedagogical point of view should supply an answer to the question. Who needs to be taught as deaf-blind?" (p. 70)

Many administrators in the United States and Canada want a simple measurement by which they can be assured that the costly programs that are being proposed are being proposed for the right population and that this population cannot be served by existing programs designed to serve other disabilities. They are often reluctant to identify infants and children as deafblind either because they do not wish formally to identify another category or because of the cost involved in the specialized services required by this unique population. They often try to rationalize this decision by pointing out that the individual[s] has some usable vision and/or hearing.

In my experience as a consultant, I have refined my presentation concerning the identification as to whom should be served as deafblind to two questions when I am working with professionals and administrators whose expertise lies primarily outside of the field of deafblindness.

- Does [the individual in question] have sufficient vision to permit him [her] to fully function as a hearing impaired person without any significant problem?
- Does [the individual in question] have sufficient hearing to permit him [her] to function as a visually impaired person without any significant problem?

If they cannot answer yes to both these questions without reservation, the individual should be considered deafblind.

Scandinavian Definition

The Nordic Council of Ministers, on the advice of the Nordic Committee on Disability representing Norway, Sweden, Denmark, Finland, The Faeroes Islands, The Aland Islands, Greenland, and Iceland, have adopted a definition of deafblindness that is forming a focal point for the study of those who are deafblind for various professional groups. The Nordic definition states that a person is deafblind when he or she has a severe degree of combined visual and auditory impairment. Some people who are deafblind are totally deaf and blind, while others have residual hearing and residual vision. The severity of the combined visual and auditory impairment means people who are deafblind cannot automatically use services for people with visual impairments or with hearing disabilities. Thus deafblindness entails extreme difficulties with regard to education, training, working

life, social life, cultural activities, and information. For those who are born deafblind or who become deafblind at an early age, the situation is complicated because they may have additional problems affecting their personality and behavior. Such complications further reduce their chances of exploiting any residual vision or hearing.

Deafblindness must therefore be regarded as a separate disability that requires special methods of communication and special methods for coping with the functions of everyday life. (The Nordic Committee of Disability is an institution for Nordic co-operation subordinated to the Nordic Council of Ministers, [i.e., the Governments of Denmark, Finland, Iceland, Norway and Sweden]. Postal address: The Nordic Committee on Disability, Box 303, S-161 26 Bromma, Sweden.)

A group of leading Scandinavian ophthalmologists and audiologists held a working conference to study the Nordic definition and, as a result of their deliberations, issued the following statement as a guide to other members of the medical profession throughout Scandinavia.

1. Deafblindness is a separate disability. It is characterized by the following criteria:

- Serious problems in relation to communication with the environment
- Serious problems in relation to orientation in the environment
- Serious problems in relation to the acquisition of information

2. These problems result from the *combined* [italics added] sensory disability. Deafblindness may occur separately or in combination with other disabilities.

3. Upon suspicion of a person actually suffering from deafblindness, or that it might develop in a person, the following diagnostic procedure should be carried out:

- Examination of the hearing and vision functions by specialists experienced in deafblindness.
- In addition to the medical examination there is a need for an assessment related to the three functional criteria mentioned (in 1) above. This assessment should be made by staff with special training [in the area of deafblindness] having medical, social and pedagogic background and adequate extensive education.

4. When diagnosing one will find persons that fulfill the three functional criteria of deafblindness, but when using the *current* [italics added] medical methods one cannot register impairments of sight and/or hearing. These persons are also to be considered as being deafblind.

5. As deafblindness is a separate disability, all persons who are deaf-blind, regardless of where they live, regardless of age and eventual [possible] institutionalization, should have access to special habilitation and rehabilitation (special aids, special teaching, special housing conditions etc.). (Statement issued at the conclusion of the Working Conference for Medical Specialists, Dronninglund, August, 86.)

The statement represents the first time a group of internationally distinguished medical professionals have addressed the problem of deafblindness. As such, it represents an important milestone in the development of services for all those who are deafblind.

Deafblindness: A Low-Incidence Disability

Deafblindness is a low-incidence disability. This obvious statement has several implications. This fact has proved to be one of the most potent arguments to help individuals and groups to establish services in both the United States and Canada, because one can reassure administrators that they are not opening the door to a flood of requests for services. In fact, careful presentation of this information has been the most singly important element in assisting in the establishment of services.

Mr. Collins has already identified many of the problems that result from deafblindness being a low-incidence disability in the areas of staff training, program development, the dispersion of clients, particularly of infants and children who are congenitally and early adventitiously deafblind, and often the chronic lack of funding because of the low of number of individuals available for advocacy.

Dr. Thomas Clark, of the University of Utah has pointed out another result from this low incidence that is often overlooked or whose importance is not recognized. There is no pool of community knowledge available to those parents or professionals who are involved with those who are congenitally and early adventitiously deafblind.

Programs of Support

Regional and State Networks

The importance of this problem was recognized by the early pioneers in the development of services for infants and children who are congenitally and early adventitiously deafblind in the United States. They developed the network of regional and state centers that was described by Mr. Collins. This network represented perhaps the most carefully thought out solution to this problem of a lack of a pool of basic community knowledge that has been developed to date here or elsewhere. It should not be assumed that there has been any change in the last 25 years.

This network had the structure necessary to meet the needs of the 70s and the flexibility to successfully enter the 21st century. It represents a solution that is being developed in other countries to provide a variety of support services for infants, children, and adults who are congenitally and early adventitiously deafblind in their home and in the local school system while, at the same time, providing specialized programs and services in central locations where such services are the choice of the parents or the adult who is deafblind.

The comprehensive service program developed by Sense in the United Kingdom under the leadership of Rodney Clarke is gaining worldwide recognition for its broad spectrum of services to those who are deafblind. Its structure is evolving into a parallel of what existed previously in the United States. Based upon my experience, I would predict that any jurisdiction that faces the problems outlined by Mr. Collins will eventually arrive at a delivery structure that will closely parallel this system.

The Ontario Approach

By the late 70s, a well-developed program for infants and children who are congenitally and early adventitiously deafblind existed in the province of Ontario, Canada. Because every child in Ontario is entitled to enter school and because parents of children who are congenitally and early adventitiously deafblind are free to choose to use either a centralized program such as the deafblind unit at the W. Ross Macdonald School or to have their child who is deafblind attend a

local school, it was decided to develop a support system to provide services from the age of identification onward. I was fortunate enough to be given the position to head up a team to make this a reality.

After analyzing the situation, we began our system development using basic assumptions derived from the status quo:

1. Community programs for infants and preschool children would not be likely to have professionals trained to work with infants and children who are deafblind. If these professionals were appropriately supported, they could use their expertise to foster intellectual growth and physical development in infants and children who are deafblind.

2. When the child reached school age, if the parents chose to have the child attend their local school, the classroom teacher would not be a trained teacher of those who are deafblind nor would she or he have access to such a trained teacher on a daily basis.

3. Special classes designed to serve children with other disabilities, while having a low teacher-pupil ratio, would probably not be the best placement for a child who is deafblind.

4. Only one school board in the province had a sufficient number of pupils who are deafblind to warrant development of its own group of professionals and support system.

5. Neither specialist teachers from deafness, blindness, and other disabling conditions, nor generically trained special education teachers were equipped to program for pupils who are deafblind in the regular classroom.

6. Parents and families required as much support as classroom teachers within the educational system if the child was to be successfully integrated into the local community and the school system.

7. An individual program and an accompanying delivery system must detail five-year goals, 12-month objectives and specific success indicators to be observed at each step.

8. Each program should receive the support of a trained professional at least once every two weeks and should have a specific professional to contact should problems arise between visits.

9. The infant or child who is deafblind can be successfully integrated into the local school system and the community if a multilevel support system is built on these assumptions.

10. As more and more children who are deafblind are successfully attending their local school, more and more parents will opt for this approach for some or all of their child's education.

11. Most important, all children would require the support of trained interveners in the home, classroom, and community setting regardless of the choice of educational setting made by their parents.

The final model we developed integrated a variety of approaches. The model was sufficiently flexible to permit the development, implementation, and evaluation of individual programs for each infant and child who is deafblind in the province as soon as they were identified. The model was based upon a sound philosophical base and implemented by staff with differing levels of training.

It was evident from the first that we could not turn every person who would come into contact with the infant, child, or adult who is congenitally and early adventitiously

deafblind into a professional with sufficient background and expertise to deal with all persons who are deafblind. Our mandate was to educate and advise parents and siblings how best to deal with their child; to support the classroom teacher so that she or he could provide day-to-day guidance and support for the individual pupil who is deafblind and the intervener; to work with therapists and other professionals to educate them as to how to apply their expertise to the individual; and to provide information to members of the medical profession that would enable them to deal more successfully with the patient.

Our mandate also required us to develop a specially trained group of professionals to deliver this service throughout a province that is approximately one sixth the size of the continental United States. We started with teachers, social workers, and care givers who had a minimum of three years hands-on experience. They then received additional training in such areas as program development, implementation and evaluation; school board structure and etiquette, family dynamics, individual training techniques and suggestions for dealing with other professionals. We also encouraged these professionals to maintain a close liaison with the pool of expertise that existed in the deafblind program at the W. Ross Macdonald School.

These professional consultants worked with both the parents and the teachers to develop a program designed to meet the needs of each child, to be delivered in the home, the community, and the school setting. (Any program designed for implementation in an educational setting *only* is sure to fail in the long run.) During their bi-weekly visit, the consultants were also available to accompany the parents and child on visits to medical facilities and to assist the parents in developing a support network to which they could turn for assistance and advice.

To support this system in between the consultant's visits, we developed a group of locally trained people for each child. These local individuals provided the support necessary to permit the infant or child who is deafblind to function successfully in the least restrictive environment. Because the Ministry of Social Services, community agencies, school boards, and others wanted a job title for these individuals we called them interveners.

Intervention

Intervention has been called a Canadian approach to providing support for persons who are deafblind. In truth, there have been interveners and intervention as far back as one can find written records of successful individuals who are deafblind. What we did was analyze the techniques and methods of working with persons who are deafblind that had been successful with individuals who are deafblind of various ages. We then gave these techniques and methods a name: "intervention."

The idea of codifying the methods and techniques arose out of the international conference held in North Rocks, Australia, in 1976. Dr. Mike Myers presented a paper "Where Are They Now?" in which he showed that over 90% of the graduates from educational programs were institutionalized within five years.

Our first reaction to the paper was that we should change our focus and begin teaching our young people who are deafblind to survive in an institutional session. However, I also met Dr. Richard Kenney, Superintendent of the Hadley School, at the conference. Dr. Kenney was deafblind.

As I communicated with him using a combination of finger spelling and a teletouch, a young lady was finger spelling into his other hand from time to time. When I asked about this, I was informed that he was receiving the same information from his "young lady" that I was observing and hearing using my eyes and ears.

When I returned to Canada, I began researching the lives of other successful individuals who are deafblind. It quickly became evident that whenever there was a successful person who was deafblind there was one or more nondisabled persons who provided information and support. The question immediately arose, "If the most brilliant and successful persons who are deafblind needed this type of support, how could we expect our infants and children to succeed with less?"

After extensive analysis, long discussions with both individuals and professionals who are deafblind in the field, and numerous attempts, we distilled the role of the intervener to three main actions. The intervener provides the following:

- Sufficient nondistorted information to enable the individual who is deafblind to make age-appropriate decisions
- The motivation to act upon those decisions
- The support necessary for the individual who is deafblind to carry out the actions arising from his or her decisions successfully in a reasonable amount of time

The methods and techniques used to carry out these responsibilities differ according to the age, the needs, and the level of functioning of the infant, child, or adult who is deafblind. Mother will in all probability be the child's first intervener. She will need formal education, training, and support in a far greater degree than that required by parents of children with other disabilities because these parents have alternative sources of information from the community pool of expertise. As the infant grows and develops, other members of the family, and later the extended family, will require the same type of support if they are to provide effective intervention. Because the intention is to supplement and not to replace community resources, preschool workers, physio- and occupational therapists, and other community professionals must receive training and support so that they also can provide intervention and use their expertise effectively. And when the family is ready, individuals will be hired by the family and then trained to provide intervention and deliver the program for this particular child who is deafblind. As new individuals are hired, they also will require training and support to provide intervention and implement the program that has been designed for the person who is deafblind. Eventually, the individuals who are deafblind will able to carry out much of this training themselves. At present we have many adults who are congenitally and early adventitiously deafblind who are involved in interviewing, selecting and training their interveners.

In the early 80s, A National Task Force on the Needs of the Deafblind traveled across Canada and received presentations from parents, and professionals, and from youth and adults who are deafblind. The report that the task force produced was called "Intervention is the Key." The main thrust of the document and of the presentations of persons who are later adventitiously deafblind, as well as those who spoke for persons who are congenitally and early adventitiously deafblind, stressed the need for intervention or support which the individual who is deafblind or their advocate

could direct, control, and utilize according to his or her own needs.

Conclusion

In conclusion, I can only restate that Mr. Collins has identified the problems, proposed a philosophical approach that is in tune both with society and reality, and laid down a framework that can and should serve as a starting point to develop a nationwide support structure for training, programming, research, and information exchange. The challenge is to turn this paper into reality.

If I can leave you with three thoughts, I would wish them to be the following.

1. Deafblindness is a unique disability that cannot be served by programs designed to meet the needs of other disabling conditions.

2. Infants and children who are congenitally and early adventitiously deafblind will not become adults who are adventitiously deafblind. In other words, programs that meet the needs of adults who are adventitiously deafblind will not meet their needs.

3. The approach taken to develop services for persons who are deafblind must not be fragmented among a number of levels or types of service providers.

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INDEPENDENT LIVING: PRESENTATION

Bernadette M. Kappen

Abstract: The overall goal of an individualized education program is to foster independent living skills, especially in the following areas: self-care/home and personal management, recreation and leisure, orientation and mobility, transportation, and technology. To improve self-care skills, we need to develop teacher training modules, promote the use of a functional curriculum approach, develop resource materials for teachers and parents, provide more support for parents, and develop a resource catalog on technical aids. In the area of recreation and leisure, training modules should be developed for use with all ages along with increased awareness of the importance of recreation. To improve orientation and mobility, materials and courses need to be developed, and electronic tactile and auditory travel devices should be improved. A special study group should be established to study the transportation needs of this population. Finally, those who are deaf-blind need improved access to technological equipment and better awareness of its availability.

Students who are deaf-blind have a variety of learning needs. Depending on the strengths and needs of each person, selecting an individualized education program can be a difficult and complex task. However, we must keep in mind that the overall goal of all the programs is to foster independent living skills. This paper reviews a variety of areas in which training can assist a person to achieve this goal. We hope that, by focusing on future needs, the children currently in school will have an improved quality of life.

Self-Care Skills/Home and Personal Management

The Current Picture

Programs for students who are deaf-blind have often included training in self-care skills as a major focus of the overall curricula. The skills of dressing, grooming, toileting, dental hygiene, feeding, and doing very basic household chores have received the most emphasis. The importance of teaching self-care skills to students who are deaf-blind has been recognized for a long time. When the regional centers were first established, professionals had an opportunity to attend workshops dealing with self-care skills. Several monographs were developed discussing how to break down the skills and teach specific skills to children who are deaf-blind. Research indicates that the basic goal of education should be to prepare students to handle the rights and responsibilities of adult life and to help individuals develop the dependence that is necessary to maintain a high quality of life (Falvey, 1989).

Professionals and family members agree that children should have every opportunity to learn basic self-care skills. However, professionals often have a difficult time determining what skills to teach and what constitutes mastery of the skill. In reviewing many individual educational plans (IEPs) it is evident that skills are not always taught with mastery in mind. It is not uncommon to read a goal that states "Eric will be toilet trained 50% of the time." Working on a 50% success rate will not allow for greater independence. In an adult situation, a person is either toilet trained or not toilet trained.

In selecting other self-care skills, like feeding, bathing, and dressing, programs often follow a strict task analysis protocol for teaching the skills. Mastery of the skill is not always equivalent to independence. A student may be able to perform a skill in a highly structured setting, but the same student may be unable to perform the task at home or in the community.

A current "best practice" in education is to offer a functional curriculum to students with vision and hearing impairments. A functional curriculum is age appropriate, relevant to performance in a variety of settings, reflects the impact of transition to the next environment, and is meaningful. An important aspect of the functional curriculum is the emphasis on choices and teaching in natural environments. The areas of self-care skills and home and personal management fit well into this functional curriculum approach. Skills to teach are selected based on a student's needs and on the preferences of the parent and student.

Learning self-care skills will enhance a student's self-esteem and feelings of competence. Developing self-esteem is essential for all students and the functional curriculum encourages participation rather than exclusion. A functional curriculum is designed for all students of every age regardless of the severity of their disabilities. Students who are deaf-blind, who are unable to perform steps of a skill sequence independently, are provided with physical, structural, or instructional adaptations that enable them to participate.

In determining if a self-care skill is functional for an individual, the teacher and parents can ask the following questions:

- If the student cannot perform the skill, is it important enough to have someone else do it for him (Brown et al., 1979)?
- Can you see yourself performing the skill in everyday life (Wilcox, 1989)?

To allow for participation in self-care activities, the following adaptations can be used:

- use of physical and prosthetic devices
- altering skill sequence
- providing instructional prompts
- altering environmental conditions

Examples of ways to simplify a task include using tactile cues on objects to help a student locate a specific item, using blenders and other electrical appliances that can be operated by a microswitch, and using color contrast in the environment to assist the student. Adaptations should be selected if the student will be excluded from an activity without the use of an adaptation (Kansas State Department of Education, 1987).

Teaching self-care skills is one of the most natural ways to teach communication skills. If a functional approach is used, communication opportunities are available on a very consistent basis. Communication skills and self-care skills are essential for future success for the person who is deaf-blind.

In selecting the curriculum for self-care and personal management, an area often overlooked but extremely important is learning to respond to emergency situations (i.e., fire drills) and developing skills in simple first aid issues. In reviewing the literature, very little is available in this area.

Future Needs

Inclusion in teacher training programs. These programs should include modules on self-care and personal management with

specific strategies on how to use the functional curriculum approach.

Development of resource materials for teachers and parents. With the exception of a recent curriculum developed at Perkins School for the Blind and older monographs, very little printed material exists specifically for students who are deaf-blind. The materials available tend to focus on the visually impaired, mentally retarded, and severely disabled. Offering competitive grant opportunities to develop materials (print and video) will assist in appropriately teaching skills in self-care and household management.

Support for parents. Parents of young children who are deaf-blind need support in managing the self-care needs of their children. Written material is extremely limited. If children are to gain competence in this area, parents need information in the early years. Formation of a parent task force to identify needs and develop materials that can be shared with the parents shortly after birth will help create a feeling of hopefulness for parents. It is essential to assist the parents in developing an attitude that their child "can do."

Development of a resource catalog on technical aids available to allow a person who is deaf-blind to participate in self-care and home management skills. Currently catalogs are available for individuals with visual impairments but there does not exist a single source for individuals who are deaf-blind to review what is available. Students and family members should have opportunities to see the devices available. Often individuals who are deaf-blind are unaware of safety-alerting devices and household aids which can assist them in performing daily household tasks.

Opportunities for practice. Students who attend specialized programs usually have many opportunities to practice and learn self-care skills. High quality programs for students who are deaf-blind are not readily available in most school districts. If the student who is deaf-blind is also profoundly retarded, nonambulatory, or medically fragile, the opportunities are almost never available. The issues of retardation may be addressed, but the child's vision and hearing impairments are not considered. Currently, many school districts have a difficult time offering programs to children who are profoundly impaired or medically fragile. With this in mind, it is clear that children with the additional impairment of being deaf-blind are not even given a chance to be successful.

In planning for an appropriate placement, the skills and willingness of the staff to work with a child who is deaf-blind must be considered. Self-care and personal management skills are essential for a good quality of life and a child who is deaf-blind needs ongoing, appropriate training.

The Education Department has recently said that schools should act with caution before placing children who are deaf with their nondisabled peers. In a policy statement, the department said that deaf students' unique needs mean they don't always reap the same benefits as other disabled children in regular classrooms. Instead, the Education Department says, schools need to put more emphasis on the IDEA (Individuals with Disabilities Education Act) mandate to offer an "appropriate education."

If this is the stand being taken for children who are deaf, what consideration is being given to children who are deaf-blind? For many years children who are deaf-blind have been placed with children who are mentally retarded. Their unique needs of communication and specialized training in self-care and personal management are not being met.

To be sure that a child who is deaf-blind is offered an appropriate placement and is receiving high quality services, the Education Department should require that schools include experts in the field on every team writing an IEP for that child.

The expert must be knowledgeable in deaf-blindness; it must not be one person who is an expert in blindness and another person who is an expert in deafness. The combination of the disabilities is a unique problem, and the understanding of the impact of the dual sensory impairment is essential for appropriate programming in the self-care area.

Recreation and Leisure

The Current Picture

A person's quality of life is enhanced by recreational experiences. For young children, free time, as well as many opportunities for learning, is often referred to as play. Leisure time for adolescents and adults is defined as free time as a result of temporary exemption from work or duties in the home.

Recreational experiences provide opportunities for self-esteem, self-expression, social interactions, and relaxation. Children and adults who are deaf-blind are entitled to satisfying recreation experiences. However, individuals who are deaf-blind have long been systematically excluded from actively participating in normalized recreation activities in community settings (Certo, Schleien, & Hunter, 1983). Starting with young children, recreation should provide opportunities for relationships with peers. The real goal should be to develop friendships.

Recreation is a frequent topic of discussion in educational rehabilitation programs; however, it is infrequently integrated into the person's individualized program. When individuals have severe sensory impairments and limited communication skills, planning recreational activities can be overwhelming for parents and service providers. Currently you can go to a neighborhood bookstore and find a book on almost any type of leisure activity; however, books specifically related to modifying recreational activities for individuals who are deaf-blind are extremely rare.

The current literature indicates that recreational programming for individuals who are deaf-blind requires structured programming. Areas needing consideration include assessment, adaptations, modifications, training, support, and follow-up activities (Everson, & Enos, 1992).

Leisure time is often equated with having fun. This should be the ultimate goal for an individual; however, it may be necessary to teach young children, adolescents, and adults how to do specific activities to allow them to have fun. In recent years, the literature has focused on recreation for adults who are deaf-blind and severe disabilities. If an individual is to learn about the vast number of recreational options, structured programming must begin with the infants and toddlers who are deaf-blind. A common and very real concern of many parents is that their sons and daughters are unable to occupy themselves. When left alone, they often engage in self-stimulatory and inappropriate behavior. The parents of young children say "my child cannot play," and the parents of older children voice their concern for their children's inability to select free-time activities.

Recreation is the perfect avenue for helping children to make choices and to indicate

preferences. These skills are only possible if the children are offered appropriate programming. Recreational activities should build respect and competence through age-appropriate activities. As a result, recreational experiences become pleasurable (fun).

Wehman and Schleien, in 1981, offered strategies to promote recreation. They suggested that the following be considered:

- assessing an individual's recreation preferences
- adapting leisure skills to allow for full or partial participation
- providing systematic instruction
- ensuring a balance between active and passive activities
- teaching individual and group recreational activities

Future Needs

To allow individuals who are deaf-blind to learn a variety of leisure skills and to participate in community activities, the following will be necessary:

Infants and toddlers.

- Provide parents and professionals access to training in play with specific modifications for children with severe sensory impairments.
- Work with community programs such as YMCA tot swim activities, gymboree and other early motor development programs to include children who are deaf-blind. While working on this project, families need to be assisted in developing advocacy skills and assertive approaches in order to access community activities. It is essential to establish the feeling that the child who is deaf-blind has the same right to play in community environments as a typical child.
- Require that all IFSPs (Individualized Family Service Plans) review the child's leisure needs.
- Integrate recreation opportunities into functional physical and occupational therapy, language and communication, and orientation and mobility programs.
- Offer competitive grant opportunities to develop training modules for staff to assist infants and toddlers to develop age-appropriate skills.

School aged children.

- Include recreation and leisure skills in each student's IEP.
- Offer training opportunities for staff and parents to learn how to modify activities and environments to allow participation in recreational opportunities.
- Work with playground companies and rehabilitation engineering programs to encourage them to develop playscapes that are more tactile and visually stimulating.
- Increase the number of hours spent in the community participating in recreational activities during the school day.
- Develop recreational curriculum guides for individuals who are deaf-blind. The curriculum should offer language and communication hints, possible environmental modifications and equipment adaptations.
- Work with community museums and cultural centers to make their exhibits

more accessible to students who are deaf-blind.

Young adults.

- Work with clubs and organizations for those who are deaf to encourage participation of individuals who are deaf-blind in social activities to reduce isolation.
- Through personnel preparation programs, design programs to train recreation therapists with basic information on how to adapt a program for individuals who have no formal communication methods.
- Train rehabilitation personnel in the area of recreation. They must recognize the need to include systematic training in an individualized plan. Individuals who are deaf-blind who have special recreational talents can be featured on local news shows to raise public awareness.

Orientation and Mobility (O & M)

The Current Picture

Current curriculum models stress the development of instructional goals and programs that increase the student's ability to participate to the fullest extent possible in domestic, recreational, community, and work activities. This participation in a variety of environments makes safe, efficient mobility an important goal for students. A large body of literature exists on strategies to teach orientation and mobility to students with visual impairments, but very few studies are available on how to teach orientation and mobility to students who are deaf-blind.

Since the 1960s there has been an expanding application of orientation and mobility techniques to individuals with multiple impairments and this includes individuals who are deaf-blind. Being developmental and sequential in nature, instruction typically stresses the acquisition of certain prerequisite skills. Many people who are deaf-blind and mentally retarded may never acquire the prerequisites to begin travel skills. Another factor that may exclude a person who is deaf-blind from receiving appropriate orientation and mobility skills is the heavy reliance on verbal instruction and verbal feedback (Lolli, 1980).

For a student to be successful in an orientation and mobility program, the instructor must be competent in teaching the technical skills as well as in communicating with the student, using the appropriate communication method. This element is currently a barrier in delivering high quality services. AER (Association for Education and Rehabilitation of the Blind and Visually Impaired) and the Council of Schools for the Blind have reported on the severe shortage of orientation and mobility instructors. This shortage is even more serious when training a person who is deaf-blind. Orientation and mobility personnel rarely have the knowledge of the communication systems the students are using. Electronic mobility devices such as the Mowat Sensor, sonicguide, path sounder, laser cane and the Polarion can enhance a person's mobility potential but, once again, the instructors may have limited training in using these devices.

With the increase in more functional programming models, some authors have suggested that adaptations to the standard O & M practice be made and that "route travel" be taught to individuals in order to increase their independence (Hill & Ponder, 1976).

Many individuals who are deaf-blind have additional disabilities (physical challenges, mental retardation, health concerns) and require a team approach to deliver effective O & M services. Some programs have been

observed to use a multidisciplinary delivery model but efforts must be directed at developing a more integrated approach. In planning a mobility program, the O & M specialist, teacher, occupational therapist, and physical therapist should coordinate the program.

The availability of research and curriculum materials is extremely limited. Currently the American Foundation for the Blind is preparing materials in the area of Orientation and Mobility. This will be the first comprehensive study of O & M for individuals who are deaf-blind.

Some young adults who are deaf-blind are interested in using a guide dog to assist them with increased independence. Unfortunately, the current training programs are set up to work with individuals who have hearing and speech capability. A few training programs will accept individuals who are deaf-blind, and the skills are then taught using an interpreter. In talking with individuals who have participated in some of the guide dog programs, they have indicated, however, that an interpreter was not available during some of the class sessions or for informal discussions with the instructors.

With the implementation of P.L. 99-457, young children who are deaf-blind are receiving early intervention services; however, the availability of services related to orientation and mobility is extremely limited. Services to young children with visual impairments have only recently received attention since. Hill and his colleagues developed the Peabody Mobility Scales in 1989. Currently, professionals are not able to access any mobility training literature for young children who are deaf-blind.

Since freedom to explore and move around safely in a variety of environments are essential elements for an individual to have a good quality of life, individuals who are deaf-blind must have access to orientation and mobility services and to trained professionals.

Future Needs

Development of materials. Parents and professionals must receive materials to help them learn how to offer appropriate services to children who are deaf-blind.

Course requirement. All orientation and mobility teacher training programs should offer a course on teaching O & M to individuals who are deaf-blind. The course would also familiarize the instructor with the variety of communication methods the students may need to use.

Development of a monograph. This document will describe how to set up tactile indicators in school and home settings to assist individuals who are deaf-blind to move more independently and to locate areas.

Inclusion of environmental information. Individuals who are deaf-blind miss visual information when traveling. In training programs, instructors need to be aware of the need to offer information about the environment.

Further development of electronic tactile and auditory travel devices. These will supplement what the child naturally receives through the senses.

Awareness of importance. Generic special education teachers must be made aware of the importance of orientation and mobility. This is essential since many children who are deaf-blind are receiving services in general special education programs rather than in a specialized setting.

Transportation

The Current Picture

Transportation is often an issue for individuals who are deaf-blind. It can start with the infant or toddler who lives in a rural community and cannot easily travel to the early intervention program. It can continue as the person gets older.

Students who are deaf-blind are provided transportation to school as part of the IEP process. The bus or car may be available but other issues need to be reviewed. If the child has physical needs, a lift bus or a vehicle with special seating may be necessary. Children spend anywhere from half an hour to many hours a day on a school vehicle. It is important that the aide on the bus has awareness of the child's needs and communication needs.

Community-based programming is viewed as the best way to teach students to become more independent and competent members of their own communities. Accessing the community requires transportation and creative solutions to complex transportation needs.

With the implementation of ADA (Americans with Disabilities Act of 1990), transportation accessibility is being addressed; however, the unique needs of people who are deaf-blind may be overlooked unless consumers, family members, and advocates participate in planning efforts. Several areas need attention in considering transportation accessibility:

- communication with transportation system
- availability of public transportation in the community
- physical accessibility and safety
- personal assistance while traveling
- cost

An issue of concern for children and young adults who are deaf-blind is the need to have personal assistance. Many individuals cannot travel independently and need to have a companion while traveling. In some situations where a person may be capable of traveling independently, the carrier *requires* a companion. The additional support is costly. If people who are deaf-blind are to have the same access as a typical citizen, arrangements need to be made for the travel companion to have a free or reduced fare.

Future Needs

A special study group (parents, consumers, and professionals) needs to be established to study the transportation needs of individuals who are deaf-blind. The body of literature on this topic is limited. Before groups without knowledge of the population try to set up transportation accessibility for individuals who are deaf-blind, those in the field must study the needs and develop possible solutions.

Technology

The Current Picture

Technology offers individuals with severe disabilities new and expanded opportunities to participate more fully in everyday life. This opportunity is very limited for some individuals who are deaf-blind. In reviewing the *Handicapped Users' Database* and the *IBM Resource Guide for Persons with Visual Impairments*, it becomes evident that access is limited for individuals who are deaf-blind who cannot read braille or large print.

Technology for individuals with visual impairments has been improving on an

almost monthly basis. The following equipment allows access to printed materials:

- speech synthesizers
- screen reading programs
- enlarged output

If a person who is deaf-blind is able to read braille, the screen can be accessed by using a braille display processor or a braille interface terminal. The Versabraille II is available to individuals who need to use braille for communication purposes. Over the last five years, the Telebraille device has been upgraded and offers a person who is deaf-blind access to the telephone as well as an alternative way to communicate with family members and to participate in activities where interpreting is not made available.

Future Needs

Improved access to equipment. Many children who are deaf-blind have additional disabilities and are not readers. The presence of two severe sensory impairments and additional disabilities limit the child's access to standard equipment. Programs designed to use the touch screen and switches to assist nonreaders require that the individuals be able to see the screen or respond auditorially. Finally, the auditory programs are not loud enough for students with severe hearing impairments.

Careful evaluation of equipment. All information about equipment for children who are deaf-blind must be evaluated from the perspective of a dual loss. Individuals who are deaf-blind differ enormously in the nature, degree, and history of their disability as well as in their abilities and needs. Careful assessment is essential in selecting equipment for communication and learning. There seems to be a paucity of equipment, and what exists will not benefit all individuals who are deaf-blind.

Awareness of availability. Technology is currently assisting the average person in performing everyday activities. This opportunity is restricted, however, when the individual is deaf-blind. Currently individuals who are deaf-blind can get information from tactile devices to be alerted to fire emergencies and other environmental sounds. Even though the materials are limited, the use of the equipment is more limited than necessary because people are unaware of what equipment is available.

Summary

All programs in an individualized educations program must speak to one goal—that of fostering independent living skills. Those areas in which skills must be developed are self-care/home and personal management, recreation and leisure, orientation and mobility, transportation, and the use of technology.

Training and services in these areas currently fail to meet the unique needs of those who are deaf-blind. Accordingly, I have presented several ideas that require action or attention from all of us who are concerned about this population. By focusing on the future, we can enable those children currently in school to look forward to lives of higher quality.

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INDEPENDENT LIVING: REACTION

Harry Anderson

Abstract: In order to teach independent living skills to our children who are deaf-blind, we need to recognize the importance of certain qualities of life that many of us who are not disabled take for granted. We must give these people the feelings that they are loved and that we have high hopes for their futures. In addition, we must give parents and children ways to manage stress, the opportunity to develop a sense of humor, techniques for sharing responsibility, methods for seeking information, and tools for making friendships. Finally, our politicians and policy makers need to consider all aspects of this population's problems so that services will be integrated and holistic in nature.

Sometimes those of us who are sighted, those of us who can hear, take independent living skills for granted. Here are a couple of examples that I can show you of what independence is supposed to mean. I have a very supportive family—a wife, and two sons, all three are deaf—who always make sure that the father and the husband can be just as independent as everybody else.

In the past, before I became blind, I used to have rows of shoes in my closet, and instead of looking to make sure I got the right pair of shoes on, I would just feel them with my feet and pick the most comfortable pair. Then, one day I went to work, and I had to go to another building to talk with somebody. Then I came back, and as I sat down I happened to look down. I had one brown shoe and one black shoe. And I said, "Well, thank God nobody saw me." After I said that, my phone rang. I picked up the phone and it was the person I had seen a few minutes before. She said, "Harry, are you aware you are wearing one brown shoe and one black shoe?"

Here's another example. They train people who are deaf-blind to be so independent that I can walk into any public bathroom and find whatever I need to go to. The biggest problem is not finding where I need to go, it's finding the paper towels. I'll be washing my hands, and I'll be walking around, water dripping on the floor, to find the paper towels.

The public reaction to a very independent person like me is interesting to see.

Public awareness is probably the most important thing we need to really address, because, as I said, independence is very important. I can explain to you certain devices such as a check writing guide. Many of us know what they look like. This guide is a mask to put over a check with a little place where you can write in the date, the name of the payee, the amount of dollars, and so on. Every time, something happens, and this has never failed, believe me, in the last 10 years since I have given up driving. I carry with me a bona fide Florida identification card, not a driver's license. Every time I make out a check, I will have either my wife with me, signing into my hand telling me how much the price is, or I will have my cane, or I will have my seeing eye dog. The salesperson must be very aware that I am blind, and she can also see this check writing guide. You guessed it. Every time she asks for my identification, she says, "May I see your driver's license?"

Before I hit the highlights of what it requires to have independent living skills, let's pretend that Harry Anderson was a very

young boy the last 10 years. Yes, I was an adult, but I mean that in the last 10 years I had to learn to work on these blind skills. So you can just sort of sit back, relax, close your eyes if you want. Except for those who are deaf-blind and who are deaf; I'm sorry, you have to watch.

I want you to sit back and relax with me and just imagine I was about six or seven years old. This is to give you an idea what I could learn with independent living skills. But before I do, I would like to show you a transparency. You have exactly one second and what you are going to see is an optical illusion. Don't share with the person next to you, or your seat mate, but what you will see is two possible pictures. In that one second I want you to focus on the screen and ask yourself what you saw. OK. Ready? Thank you. Some, I know, without question, probably saw two faces. Some of us probably saw a vase and again, some of us probably saw two faces *and* a vase and were thus able to look at both sides.

The purpose of showing the transparency is to let you know we still have a long way to go in teaching our children who are deaf-blind independent living skills. We've got a long way to go to teach the public that people who are deaf-blind can and should be allowed to live independently. We need to change some attitudes. We need to teach people not to look at one thing only. They need to look at all sides.

Now, I want to ask everyone of us to sit and imagine with me again. What makes a person who is deaf-blind a successful, independent, person in our community? I will just imagine we're building a brick wall. Not to stand on, but to build a person. Now, listen and imagine we have a brick. The very first brick has one word on it—"love." The corner-stone of that successful person who is deaf-blind is love. We've got to teach our children who are deaf-blind that they are loved, and that they should learn to love back. We've got to teach our children who are deaf-blind to love themselves. It is probably the most important thing in our lives. Love is probably something that I will always remember because I would not be standing here today if my wife and two sons didn't give me love and support.

Now, the next brick to lay beside love is "hope." I can not help but refer to Joyce Ford's letter and her keynote address yesterday. It was from the heart. She has a dream: She wants her son to be as normal as possible. She wants a lot of things within her rights. What Joyce has is hope. Without hope, Joyce Ford and the rest of us would not be sitting here today.

The third most important thing beyond hope is "stress management." It is very difficult to be deaf-blind. I don't care whether the child was born deaf-blind or became deaf and blind later in life. This combination is not something I want, it is not something I asked for, but I've learned to manage life as a person who is deaf-blind. We all are here; we are professionals. We all know how parents are filled with strife, how other people in their lives are filled with strife, and children who are deaf-blind do pick this up. We need to help parents manage stress so their children who are deaf-blind can learn that too. We need to teach our professionals how to teach stress management to our children who are deaf-blind.

Next to the stress management brick is another one—"sense of humor." Sense of humor is probably one of the most important qualities. I live with a sense of humor. Many know me well. I have probably the best sense of humor. One lady last night (I felt very good about this) came up to me and said she likes the way I laugh. It was an honor. Why do I say sense of humor is important? Not one time during this last day

and a half did we discuss how we can teach our children who are deaf-blind to laugh. How many of us honestly have heard our children who are deaf-blind laugh? Because laughter is a learned behavior. We have to teach our children who are deaf-blind to laugh—at themselves, at things, with other people—because a sense of humor carries you forward and goes on.

Now, we have the foundation. On top of that foundation comes "sharing responsibility."

I cannot overstress the sharing of responsibility. Since I am a person who is deaf-blind, my wife has the responsibility of driving the car. I have to learn the responsibility of planning my time far in advance. We cannot allow ourselves to take all the responsibility; we must share responsibility with our children who are deaf-blind. Our children who are deaf-blind have to understand that they are going to have to lead their own lives, and they have to be responsible for themselves.

I know parents are frightened. Where will my children be 10, 15, 20 years from now? Are we going to be able to enjoy retirement? Or are we going to have our children stay at home and live with us until we die?

Beyond sharing responsibility is "seek information." All parents should seek out other parents for help.

The next is "friendship." We have talked about friendship many times in this symposium. Friendship is another important segment in our lives. We are a social creature, we thrive on friendship. We have to encourage our children who are deaf-blind to show their best side so that our sighted and hearing world , as well as our deaf world, can feel comfortable with us. We are the ones who have to teach others the meaning of friendship. Because of our disability we need to be in touch. We must make others feel comfortable enough to contact us through communication. Friendship provides therapy as well as self-satisfaction. Friendship provides sharing of joys, sadness, love, and respect. One must understand that living in the world of darkness and silence is very lonely. We must be sure that the children and adults who are deaf-blind have access to friendships.

Now, I want to move on to the next transparency. I feel I need to discuss this because it relates very well to future independent living. (I'm sure Joyce Ford wonders where I got this picture. It was just a coincidence she talked about it yesterday, and I brought it too.) To me, the elephant in this picture is the deaf-blind population in America. The blind men standing around, one holding the ear, one holding the leg, one holding the tail, one holding the trunk, are not us, not the parents, not those who are deaf-blind. Those men are our politicians and our policy makers. What we need to do is package this elephant now, go back to our respective states, and unplug the ears of our politicians. We've got to take away their dark glasses and make them see the whole elephant, not the pieces.

The reason I brought this picture is because Joyce, in her letter, wrote that we are going to present to the Department of Education the 10 most critical issues that emerge from this symposium. What jumped out of that letter is that the Department of Education is going to *prioritize*. We don't need the Department of Education to prioritize. We need it to put all 10 issues into one huge birthday cake for our children who are deaf-blind.

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ADULT SERVICES: PRESENTATION

Douglas Watson

Abstract: First, the adult service system needs to be more accessible. To achieve this, we need (a) a reliable data base on the size, distribution, and characteristics of adults who are deaf-blind; (b) better interpreter training programs; (c) technical assistance centers; and (d) improved personnel preparation programs. Second, adults should have expanded options for choice and control of services and supports. To achieve this, they must be represented on adult service advisory councils; they must participate in Individualized Written Rehabilitation Program options for choi e and control; and we must develop voucher or certificate demonstration programs. Third, in order to achieve a broad systemic and holistic model of community-based services, we must facilitate inter-agency planning and cooperation. Finally, we need to develop a consumer-driven system by promoting consumer self-advocacy and involving consumers and their families in the planning and organizing of adult services.

Fundamental changes are sweeping across America, breaking the chains of public ignorance and indifference toward people with disabilities. We are experiencing the coming-of-age of the disability rights movement in America. More and more agree that people with disabilities should have equal opportunities for full participation in all aspects of society (Thayer & Rice, 1990). Enactment of the Americans With Disabilities Act of 1990 (ADA) empowered consumers by helping people with disabilities gain control over their lives.

In P.L. 102-973, the Rehabilitation Act Amendment of 1992, Congress mandated fundamental changes that reflect values consistent with those of the ADA. The program of services authorized by the Act "empowers persons with disabilities with choice and meaningful employment, and promotes independence, productivity and full integration into the workforce and community—critical components of participation in the fabric of life in our nation" (Button, 1992, p. 3). These two powerful commitments to building a society which supports efforts to live productively challenge us to reexamine our nation's approach to education and rehabilitation services for people who are deaf-blind.

Appropriately, this planning conference has targeted 10 key areas for reexamination. Numerous issues are readily evident for each of the key areas. Our charge, in turn, is to articulate a vision that involves a fundamental restructuring of programs and services and that will enable persons who are deaf-blind to gain power over their futures.

A Population in Search of Accessible Services

Various estimates suggest there are somewhere between 30 and 45 thousand individuals who are deaf-blind in the United States (Baldwin & Bullis, in press; Ouellette, 1983; Wolf, Delk & Schein, 1982). Lacking an accurate census of this low-incidence population, the adult service system in this country rarely considers the special needs of this group for purposes of program planning and resource allocation. As a result, most programs are ill prepared to serve the occasional request for services by a person who is deaf-blind. Appropriate services are often available only for the fortunate few

who happen to live in an area that has skilled local professionals and/or programs.

Over the past two decades, major initiatives have directed the nation's adult service program staff to develop the knowledge and skills needed to serve these individuals. Considerable resources were dedicated to this objective through the development of a national "safety net" of specialized services, supplemented by technical assistance and support centers in the 10 geographical regions. The Helen Keller National Center (HKNC) and its regional affiliates exemplify the extensive investments made to implement a comprehensive nationwide program that is dedicated to enabling adults who are deaf-blind to access the adult service system. As a group, this system serves almost 2000 clients per year with several hundred placed into employment annually (HKNC, 1991). State and multi-state projects under Section 307.11 represent our national efforts on behalf of children and youth served by the educational system. Baldwin and Bullis (in press) report these centers annually serve over 7000 children and youth. These twin programmatic investments by Congress have had a significant impact on the lives of thousands. However, due to limited resources, the programs do not reach all those in need.

In an effort to patch the gaping holes in this "safety net," a continuing series of local, state, regional, and national "state-of-the-art" training and technical assistance programs have been conducted. Face-to-face and hands-on training for service personnel has been supplemented with the publication and dissemination of numerous guidelines and/or recommendations for practice, research, and programmatic approaches. Several of these merit mention. A conference on planning for the future, *1980 is Now* (Sherrick, 1974), presented recommendations for meeting the needs of children affected by the 1964-1965 rubella epidemic, as they matured. Another report, *Needs Assessment of Services to Deaf-Blind Individuals* (Wolf, Delk, & Schein, 1982), provided the field with population estimates and data on service needs. The following year, *A Model Service Delivery System for Deaf-Blind Persons* (Watson, Barrett, & Brown, 1983), provided guidelines for the planning and implementation of statewide service delivery systems. The *Eleventh IRI: Vocational Rehabilitation of Deaf-Blind Persons* (Konar & Rice, 1984), recommended guidelines for improving state vocational rehabilitation services. Another national conference, *State of the Art: Research Priorities in Deaf-Blindness* (Stahlecker, Glass, & Machalow, 1985), articulated priority concerns for future research in the field. A 1986 national conference on transition issues generated a series of papers and recommendations, *Transition For Persons with Deaf-Blindness and Other Profound Handicaps: State of the Art* (Covert & Fredericks, 1987). More recently, developing concerns with the special needs of the elderly have been expressed in publications by HKNC such as, *Identifying Vision and Hearing Problems Among Older Persons: Strategies and Resources* (Bagley, 1989) and *Beyond Refuge: Coping with Losses of Vision and Hearing in Late Life* (Luey, Belser, & Glass, undated). Collectively, these and numerous other such published guidelines, priority recommendations, and "state-of-the-art" training and technical assistance packages have generated a vast body of knowledge to guide efforts to serve persons who are deaf-blind.

As a nation, we have obviously taken some significant steps toward constructing the broad outline of an adult service delivery system. The task ahead is to fill in that broad outline with a broad systemic and holistic community-based system of comprehensive services for adults who are

deaf-blind. Given the very real restraints of finite personnel, program, and fiscal resources that are available to us, what critical issues merit priority for the next decade?

Critical Issues in the Adult Service System

My charge from the planning committee is to address critical issues related to the topic of adult services. The original list of 15 issues generated by the planning committee has been reorganized into four priority areas. These include the following: (a) improving access to the adult service system, (b) expanding options for choice and control of services and supports, (c) facilitating inter-agency program planning, implementation, and coordination, and (d) encouraging consumer participation and leadership to ensure a more consumer-driven system. This review will focus on the task of relating current practices to critical issues that need to be addressed within the Federal-State Vocational Rehabilitation Services Program and the programs associated with it such as independent living, independent living centers, supported employment, rehabilitation facilities, and related vendors. Time and space constraints dictate that only selected issues can be considered here; however, the format also provides for a follow-up reactor and focus group discussion which should allow for a wider discussion.

Improving Access to the Adult Service System

Many persons who are deaf-blind have historically found it difficult to gain entry into the adult service system due to the assumption that the severity of their dual disability precluded the ability to obtain employment and live independently (Konar & Rice, 1984). Denials of service were based on concepts of feasibility of successful outcomes, concepts which were embedded in the eligibility process for most service systems.

The 1990 enactment of the ADA, combined with the passage of the Rehabilitation Act Amendment of 1992, effectively eliminates such standards of feasibility and eligibility and replaces them with the requirement that individuals be presumed eligible for services. Specifically, the Act creates "a presumption of eligibility" for all applicants for vocational rehabilitation services who have been determined to be disabled. The presumption is that a person with a disability who applies to vocational rehabilitation services is capable of benefiting from such services. In addition, a person is presumed to have a disability if she or he has been determined to be disabled under another program. To deny eligibility the *agency must show that a person cannot benefit from its services*. If the agency cannot show this, it is obligated to develop a plan and provide services. Consistent with the values articulated by ADA, these presumptions of feasibility, eligibility, and reasonable accommodation extend into all areas of the nation's public and private adult service system.

However, a number of critical issues face persons who are deaf-blind and those who provide adult services to them.

1. Population data base. Our nation lacks a reliable data base on the size, distribution, and characteristics of adults within the population who are deaf-blind (Baldwin & Bullis, in press). The adult service system needs access to timely data on the number and needs of these individuals in order to plan and provide appropriate services. Recognizing this problem, the Rehabilitation Services Administration (RSA) issued Policy Directive 93-02 on November 10, 1992, introducing a series of new statistical codes to be used by state vocational rehabilitation

agencies in reporting case service data (RSA-911 data system) to RSA on the major and secondary disabling conditions of clients who are deaf-blind (RSA-PD-93-02). Other adult service system programs need to implement similar mechanisms to enhance the utility of their client data base systems. Even the current "guesstimates" totally omit the growing numbers of elderly individuals experiencing progressive loss of hearing and sight. Federally sponsored population censuses, studies, data bases on people served, and related programs must be mandated to collect and report reliable information related to the size and characteristics of low-incidence populations.

2. Interpreter education/training. Good communication is essential to ensure access to the adult service system, employment, and independent living. Persons who are deaf-blind must have access to skilled interpreters (Konar & Rice, 1984; Watson, Barrett, & Brown, 1983). Yet, interpreter training projects (ITP) funded by the RSA and the Office of Special Education Programs (OSEP) are not mandated to include in their curricula an emphasis on interpreting for persons who are deaf-blind. The 1992 Act added language expanding the number of ITPs that the Office of Special Rehabilitative Services (OSERS) can fund and requires that the mission of the ITPs include training in interpreting with people who are deaf-blind (P.L. 102-973). Many ITPs already have excellent curricula in place; the grant program should require these materials be pooled and shared, with funds earmarked for additional pre- and in-service education and training activities by both OSEP and RSA ITPs. The field also needs to address the lack of a career path for new interpreters and the inadequate levels of compensation (Watson, 1990).

3. ADA technical assistance centers. Adult service system personnel and employers need access to training and technical assistance as they make reasonable accommodations for persons who are deaf-blind. NIDRR (National Institute on Disability Research and Rehabilitation) has funded 10 Regional Disability and Business Accommodations Centers (RDBACs) to assist consumers, employers, and service systems. To provide these centers with state-of-the-art materials on how to make communication accommodations, NIDRR has twice issued requests for proposals from the field. Not receiving any proposals that merited funding, no grant has yet been awarded (Richard Johnson, NIDRR, personal communication, September, 1992). Consumer and professional leaders must insist that NIDRR issue another call for proposals and form a coalition of experts to jointly apply for and conduct this project. The RDBACs represent one of this nation's first major initiatives toward implementing the reasonable accommodations mandated by ADA. In the 1990 Rehabilitation Act, Congress added language that also authorizes the state agencies to train employers regarding the ADA. In order to assist employers and others to make reasonable accommodations for persons who are deaf-blind or have other communicative needs, the RDBACs and state agency ADA training units will need effective materials for consumers, employers, and service personnel.

4. Personnel training in "best practices." Adult service system personnel preparation programs such as the RSA- and OSEP-sponsored pre- and inservice education and training grant programs are not providing adequate preparation to prepare general or specialty personnel in "best practices" with persons who are deaf-blind. This omission persists in spite of the fact that state vocational rehabilitation and other adult service programs identified such training as a priority almost five years ago (Pelavin, Pelavin, & Celebuski, 1987). RSA and

OSEP each year allocate millions of dollars to fund training grant programs for staff development, Regional Rehabilitation Continuing Education Programs (RCEPs), degree programs, and related training activities. We need to require that these grant programs include provisions for covering "best practices" for low-incidence populations. Perhaps the assessment and training models used by the deafness rehabilitation field as described by Watson (1990) could serve as a viable model for use with people who are deaf-blind. HKNC and other specialty programs have the materials already in place and could help training programs integrate "best practices" materials and instructional techniques into pre- and inservice curricula.

Expanding Options for Choice and Control of Services and Supports

Both the ADA and Rehabilitation Act Amendment of 1992 are predicated on the assumption that persons with disabilities be empowered with choice and control in all aspects of their lives. Title I of the Act (the Basic Program of Vocational Rehabilitation Services) specifies that individuals must be active participants in their own rehabilitation programs, making meaningful and informed choices about the selection of their vocational goals, objectives, and services (P.L. 102-973). The Act further requires the State Plan to describe the choices given and control over the determination of goals and objectives. ADA, of course, extends the assurance of empowerment through choice and control into most aspects of life.

A number of critical issues face persons who are deaf-blind as they seek options in the adult service system.

1. Representation on adult service advisory councils. Persons who are deaf-blind must participate and be represented on advisory councils so they can shape and monitor adult service programs regardless of whether or not the programs are specifically directed to serving persons who are deaf-blind (Konar & Rice, 1984; Watson, Barrett, & Brown, 1983; Wolf, Delk, & Schein, 1982). Although no data exist on which to base a definitive declaration, it would be fair to estimate that few, if any, general adult service programs make it a practice to include consumers who are deaf-blind on their advisory councils. Yet, most of these programs are funded with a mandate to serve *all* persons with disabilities, including persons who are deaf-blind. No wonder low-incidence groups are so poorly served by our nation's general service delivery system, they are too often denied the opportunity to determine the way in which those services are organized and provided. Congress mandated that the composition of various advisory councils established to guide and monitor the programs authorized by the Rehabilitation Act Amendment of 1992 must include a cross-section of representatives of disability advocacy groups (P.L. 102-973). Consumer organizations of people who are deaf-blind, their families, advocates, and professionals in the field must vigorously advocate for their rights to be represented in a meaningful way on the advisory councils of our nation's adult service system. This advocacy should be for across-the-board representation: State Rehabilitation Advisory Councils, Independent Living Councils, Supported Employment Councils, Projects With Industry Councils, Research Advisory Councils, Rehabilitation Technology Councils, Training and Demonstration Project Councils, the National Advisory Council on Disability, and numerous other groups operating on the local, state, and national level. They also need to work for representation in the OSEP and RSA peer-review process and related activities in order to significantly affect the planning, selection, and award of funding grants designed to improve the ways in which education and

rehabilitation services are organized and provided for adults with disabilities.

2. Individualized Written Rehabilitation Program (IWRP): Options for choice and control. Individual options for choice and control of services and supports were significantly expanded by Section 113 in the Act, reauthorizing the IWRP. Specifically, the IWRP must be designed to achieve the employment objective of the individual, consistent with his or her unique strengths, priorities, abilities, and capabilities. The IWRP requires a statement by the individual in his or her own words describing how he or she was informed about and involved in choosing among alternative goals, objectives, services, entities providing services, and methods used to provide or procure such services. IWRPs must be jointly developed, agreed upon, and signed by the Agency and the client or significant others (P.L. 102-973). This amendment assumes increased control for individuals in developing their own plans of services. It also promotes individual choice for a range of living options, vocational/career options, ongoing support services (personal assistance, transportation, interpreting, etc.), and empowers the individual to look beyond entry level jobs to careers. Consumers and their families or advocates must insist that the intent of Congress be fully implemented on their behalf.

As with the requirements of the existing IWRP process, the key issue here is access to information. Service providers will need to make information available through interpreting, braille or large print materials, and related accommodations to ensure that consumers know about all the service and support options they are entitled to (Konar & Rice, 1984; Watson, Barrett, & Brown, 1983; Watson & Taff-Watson, in press). The Act also stipulates that state education and rehabilitation agencies are to establish interagency IEP/IWRP plans for service. RSA and OSEP should be mandated to support programs of information, training, and technical assistance designed to educate consumers, their families, advocates, and service providers about the extent and scope of the client's right to make informed choices under the revised IWRP regulations. HKNC and NIDRR should likewise be mandated to conduct evaluative research and related monitoring programs in order to assess implementation and outcomes.

3. Client choice: Voucher or certificate demonstration programs. Research has shown that when people feel powerless, they tend to cope by trying to control others, creating defensive, oppositional, and unresponsive behaviors in others, and fueling a negative cycle that Schlesinger (1987) describes as the cycle of powerlessness. Under Title VIII of the Act, Congress has added an amendment that calls for "Demonstration Projects to Increase Client Choice." This demonstration authority would permit state agencies to apply for vouchers or certificates to be used by people with disabilities to purchase their own services. The amendment calls for strategies to increase client choice, including choice among qualified service providers (P.L. 102-973). Participation in this program would give the consumer who is deaf-blind the ultimate control in exercising personal empowerment. Consumers, along with their parents and advocates, need to encourage their state agencies to participate in alternative ways to make adult services options available. The information gained through this kind of participation of consumers who are deaf-blind could lead to a more responsive and effective adult service delivery system.

Facilitating Inter-agency Program Planning, Implementation, and Coordination

The needs of consumers who are deaf-blind are clearly diverse; these people require the resources of multiple adult service agencies. Probably the most effective approach to construction of a network of effective services has been through inter-agency planning and collaboration (Everson, Rachal, & Michael, 1992; Gottula, 1983; Konar & Rice, 1984). Although the composition of these inter-agency teams varies considerably, the agencies and individuals most often involved include representatives of the adult deaf-blind community, families, state vocational rehabilitation agencies, secondary and postsecondary education and training programs, mental health and developmental disabilities agencies, vocational education, and other allied service programs. The literature shows that inter-agency collaboration is the most productive way to improve the planning and delivery of services to persons who are deaf-blind. A national program, the HKNC Technical Assistance Center (TAC), has emerged in recent years as the leading force in assisting states or communities to plan, train, and implement inter-agency teams. Since its inception in 1984, TAC has trained 18 state inter-agency teams (Everson, Rachal, & Michael, 1992). A primary goal of these inter-agency team efforts has been to make "best practices" more readily available within the existing adult service system. TAC findings show that these collaborative efforts have consistently produced positive community-integrated outcomes for persons who are deaf-blind.

Inter-agency collaboration networks can be expanded and improved. A number of issues need to be addressed.

1. Inter-agency adult service collaboration. Although originally pioneered by HKNC and various statewide inter-agency adult service collaboration efforts (Gottula, 1983; Konar & Rice, 1984), much of the recent literature has focused on services for children and youth in transition. To their credit, it appears that efforts such as the TAC program have significantly improved upon the original concept through the years. Further, the literature implies that these activities have encompassed the needs of adults as well as youth in transition. Yet, a careful reading of this body of literature fails to provide substantial evidence that adult services have received equal attention and resources. Whatever the case, the HKNC TAC project and various other inter-agency collaboration teams have successfully demonstrated that such programs can be highly effective; in fact, these programs are perhaps the most productive approach available to the field. Priority should be given to the twin task of exporting the model to more states and expanding the scope of these efforts to include an equal emphasis on services for adults. For instance, some of the "best practices" in inter-agency collaboration programming are targeted to young adults in transition; these "best practices" need to be extended to adult services for all ages, including the growing number of senior citizens with late-onset dual loss of hearing and vision. Additional funding would obviously be needed; RSA and other related adult service funding sources should be made aware of the success of the TAC program and encouraged to allocate the funding needed to replicate and otherwise expand the program into the adult service system.

2. Broad systemic and holistic community-based approach needed. A detailed description and discussion of the numerous issues associated with the scope, mix, and quality of services most often included in inter-agency collaborations is not possible within the context of this paper. However, various combinations of the following adult

service systems are most often represented in the literature:

- Inter-agency coordination and planning between education and rehabilitation programs
- Centralized case management arrangements
- Coordinated transition from school to adult services, work, and independent living
- A wide range of state vocational rehabilitation services
- Community-based independent living centers and independent living services
- Supported and competitive employment services
- Housing and transportation assistance
- Recreation and leisure services
- Postsecondary training and continuing education
- Interpreter training, information and referral
- Assistive technology and supports
- Personal assistance services
- Services for families and parents, including respite care
- Personal futures planning

Seiler, Everson, & Carr (1992) completed a national survey of agencies that reported they provided services for persons who are deaf-blind. They received usable responses from 719 agencies distributed across the nation which provided a mix of the kinds of services listed above. When asked if they needed technical assistance to help them improve their ability to serve persons who are deaf-blind, most asked for help in a large number of areas. This great need for technical assistance suggests both that agencies are actively trying to serve these individuals and that they are aware of the need to improve their knowledge and skills to do so. However encouraging it was to find so many agencies involved in service delivery, the authors were disturbed to find that a vast majority of these programs continue to use an isolated skills training approach instead of a broad systemic and holistic model of community-based services for these individuals. In concluding their report, the authors recommended the following:

> Future funding priorities and technical assistance activities must aggressively promote holistic and visionary client planning (e.g., personal futures planning, supported living, supported employment, home school initiatives) along with broad systemic and administrative inter-agency change supports. (pp. 50-51)

Is the field prepared to take a broad systemic and holistic approach to community-based inter-agency service delivery for persons who are deaf-blind? That is clearly the direction that Congress has mapped out in the Rehabilitation Act Amendment of 1992. The broad systemic and holistic approach proposed by the Act will require a careful reading, followed by an equally fundamental restructuring of how we conceptualize and approach the delivery of services to adults who are deaf-blind. The current approach used by the TAC model for training inter-agency teams may be a good starting point. The TAC model has developed extensive networks that have demonstrated its effective implementation. How we perform this task may well be one of the most critical issues we face in the near future.

Encouraging Consumer Participation and Leadership

Tracing the roots of the development of the adult service system for people with disabilities in the United States, Thayer and Rice (1990) noted it should not be assessed in isolation from the broader disability rights movement. Reviewing this movement, they described it as follows:

> The historic and long-term drive by people with disabilities to be empowered with the rights of self-determination and control of their own lives, to become integrated as active, productive, and respected members of their families and communities . . . making cultural and life style choices among options that minimize reliance on others in decision-making and in performance of everyday activities, limited only in the same ways that people without disabilities are limited. It means exercising the greatest possible degree of choice about where you live, with whom you live, how to live, and how to use time. This includes taking risks and having the right to succeed or fail. It also includes taking responsibility for one's decisions and actions. (pp. 10-11)

The achievements of the disability rights movement in the United States are self-evident in the enactment of ADA and the current language Congress is using in the Rehabilitation Act Amendment of 1992. These achievements were hard earned, products of a drive by grassroots consumer advocates whose self-advocacy sparked the disability rights movement. However, we must not lose sight of the responsibilities that these new rights bring. First, the right to control one's own life requires assuming the responsibility for self-advocacy. Second, it assumes active involvement in general adult service system advisory councils and planning groups.

Issues related to each of these interrelated responsibilities for consumers who are deaf-blind and their families (or advocates) need to be addressed:

1. Consumer self-advocacy. Self-advocacy as used here, refers to the concept of individual and group self-advocacy which "underlies the basic philosophical and political tenets of American society: self-reliance; freedom to make choices on how to best meet one's own needs; freedom to pursue one's own interests in social, political, and economic areas . . . . The key to success in any social movement always has been and still is self-advocacy" (Funk, 1986, p. 3). If the history of the disabilities rights movement in this country has taught us anything, it is that programmatic reform can be enacted and sustained only with the active participation of the beneficiaries of that reform. We need to be sure that, whether on the individual level or in organized groups, consumers who are deaf-blind and families with members who are deaf-blind are ultimately the ones who make their own choices and define their own needs. Many are concerned with a broad range of issues, but few know how to take effective action. Too often persons who are deaf-blind have not acquired advocacy skills nor have they learned how to influence decision makers. The same observation holds for many families with members who are deaf-blind. Three of the more recent programs developed by HKNC have addressed this need in part by providing technical assistance and training workshops for consumers and families through programs such as TAC, National Parent Network, and the HKNC program for Older Persons with Deaf-Blindness (Barrett, in press). These are important resources; however, we also need to empower entire groups to assume lead roles in self-advocacy. In our field, these consumer groups are the American Association of the Deaf-Blind (AADB), and numerous local and state

consumer and parent advocacy groups. Programs and materials developed by the independent living field over the past two decades have proven highly effective and would be easily adaptable for use by consumers who are deaf-blind. A self-help manual, *Consumer Involvement in Advocacy Organizations: Rehabilitating Communities for Independent Living* (Balcazar & Seekins, 1986), provides materials in easy-to-use form to help organize advocacy groups and teach advocacy procedures. This and other training packages have been widely used in cross-disability training efforts that, unfortunately, rarely included adults who were deaf-blind. The leadership of the field needs to correct this gross disservice and give priority to establishing a continuing program of self-advocacy training for adults who are deaf-blind. Federal agencies such as OSEP and RSA should more closely monitor federal grant projects that are supposedly "cross-disability," to ensure that federal funds to such consumer groups do in fact make a concerted effort to include persons who are deaf-blind.

2. Involvement in planning and organizing adult services. If consumers and families wish to control the services and supports they need or desire, they must be actively involved in the planning and organization of those services. This basic tenet has been stressed repeatedly in the preceding review and is presented yet one more time in order to reemphasize the central importance of consumer leadership. Moreover, we perhaps need to borrow from the independent living movement by speaking out in favor of majority representation on the advisory councils of programs established specifically to serve adults who are deaf-blind. This would also include a call for strong adult consumer representation on inter-agency team efforts targeted to children and youth; surely those teams could benefit greatly from such adult input! The issue of representation is real; the field must recognize the importance of this issue. The adult service system for persons who are deaf-blind should be fully consumer-driven. By the same token, their representation on general adult service system advisory councils and planning groups also merits priority.

As a nation, we cannot afford to overlook the vast talents, motivation, experiences, and insights that only consumers can provide. Making the adult service system accessible to persons who are deaf-blind demands our best efforts. Until the adult service system is consumer-driven, we have not put the best team players on the field. In the decade ahead, if we change nothing else in the way we plan and organize adult services for persons who are deaf-blind, let that one change be to ensure that consumers and families are leading us forward.

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ADULT SERVICES: REACTION

Stephen Perreault

Abstract: Services for adults who are deaf-blind need to be more accessible as well as provide more continuity. A 1984 task force in Massachusetts examined the service needs of those who are deaf-blind and how those needs were being met. The resulting program used a system of centralized case management within a lead agency that was able to provide centralized information and referral, coordinated case management, utilization of specialty support services, and coordination of inter-agency resources. On a national level, leadership in achieving coordinated services might be provided through the Rehabilitation Services Administration (RSA). Other recommendations include improved personnel training, more choices and control of services by those who will receive them, and more inter-agency program planning and coordination. Recommendations presented in the position paper of the National Coalition on Deaf-Blindness are cited and RSA is urged to collaborate with the writers of that position paper.

I congratulate Doug Watson for his paper and comprehensive summary of current literature and practices in the provision of rehabilitation services to individuals who are deaf-blind. I was especially thankful for his analysis of legislative changes brought about through the Rehabilitation Act Amendment of 1992 and the potential benefits for persons who are deaf-blind. I will attempt to react to and supplement Doug's paper by drawing from three aspects of my personal experience (a) as a teacher of children who are deaf-blind, (b) as an administrator of an adult service program for individuals who are deaf-blind, and (c) from information gained through work with the National Parent Network and state organizations of parents of children who are deaf-blind.

Limitations in Adult Services

Much of the literature that Doug cited in his paper emanated from efforts to plan and advocate for the transition from education to adult services of the approximately 5 thousand young adults who were deaf-blind as a result of the rubella epidemic of 1964-65. This same literature detailed ranges of supported employment and living options along with social, health, and ancillary services important to the successful transition of this population. The majority of these people entered the adult service system in the years 1986-88. What happened? Giving myself the license to react both from personal experience and from experiences related by a number of parents, I would like to offer the following statements: (a) For the majority of these young adults and their families the experience was a disaster; (b) programs were not and are not in place in adult service systems, which provide for the expansion of capacities learned in education programs; and (c) services which assist in obtaining basic quality-of-life goals such as personal housing, productivity, friendships and recreation have not been accessible to these individuals due to inadequate resources, inappropriate program planning, and untrained personnel.

In addition, a working group of the National Coalition on Deaf-Blindness, in an analysis of adult services in preparation for the reauthorization of the Rehabilitation Act, arrived at a consensus on the following issues:

- There are currently no programs that prepare rehabilitation personnel to provide services to individuals who are deaf-blind.
- Rehabilitation programs often do not include components that address the specific service needs of individuals who are deaf-blind. Time-limited and current case-closure standards are inappropriate service techniques for persons with progressive sensory loss.
- Services for individuals who are deaf-blind require comprehensive planning in order to be effective.
- Supported employment has been an underutilized resource in providing vocational services to individuals who are deaf-blind.
- There is no consistent method for collecting data and tracking the experience of individuals who are deaf-blind who are receiving rehabilitation services.
- Individuals who are deaf-blind could obtain community participation through supports provided through independent living centers, yet often these services are not developed or available.
- Early planning and inter-agency coordination is essential for the successful transition of youth who are deaf-blind from education to adult services. Parent/family member involvement is necessary to formulate an individualized plan that reflects the appropriate choices and abilities.
- Persons over age 65 with dual sensory loss make up a growing population in need of services.

We must acknowledge some wonderful examples of individual successes and innovative programs. Helen Keller National Center, its regional offices and affiliate programs and Technical Assistance Centers (TAC) have done an outstanding job of providing training and technical assistance to a number of individuals who are deaf-blind, their families, and service providers. Yet I believe they would be the first to agree that we are only at the initial stages in addressing the adult service needs of individuals who are deaf-blind on a comprehensive, coordinated, and national basis.

To begin to address this as an issue that can be affected by policy statements and recommendations requires that we ask, "What is unique about the population of adults who are deaf-blind?" "What are the barriers in the adult service system that prevent the obtainment of eligible services?" and "How do we remove barriers in order to allow services to be accessible?" I agree that the passage of the Americans With Disabilities Act and congressional intent in the reauthorization process give us a mandate to proceed; however, I believe we need to be proactive in definition of service needs of all adults who are deaf-blind if they are to be included in new planning and changes.

The Population

I support Doug's call for the need for a federally sponsored database in assessing the size and characteristics of the population of adults who are deaf-blind. I would supplement this recommendation by suggesting that currently we do have a database of children who are deaf-blind and that this is a source of future information on adult service needs and experiences. This could be done by adding a five-year follow-up study mandated through state and multi-state projects under Section 307.11. These data should be available to the National Register at Helen Keller National Center.

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Before proceeding with an examination of barriers within the adult service system, there are some common characteristics that will give us a basis for discussion of accessibility for adults who are deaf-blind:

- The population of persons who are deaf-blind is heterogeneous with regard to the effects that combined sensory loss has on an individual's educational, functional, and vocational capacities. A large number of persons who are deaf-blind may have additional disabilities. Systematic programming for this population must address individual needs and capacities. Often, services need to be coordinated from a variety of sources and disciplines.

- The most common effect on people of all ages who are deaf-blind is impairment of communication. Development of communication capacities through individualized intervention is essential. Individual learning and access needs may vary, yet if persons who are deaf-blind are to benefit from services, communication assessibility and enhancement must be at the center of program planning whether it is for supported employment, independent living, or college attendance.

- Etiology may be present at birth as in rubella syndrome or later in life as with Usher syndrome or aging. In both cases sensory capacities may vary and change over time so that services which support living, work, and social goals may need to be modified.

In returning to the themes of Doug's paper, access, choices, and empowerment, I would offer communication accessibility, coordination of multiple services, and flexibility in service delivery as the means for achieving these goals through systems change and modification. I would like to illustrate this point by presenting a process of identifying and removing barriers to services for adults who are deaf-blind.

The Massachusetts Plan

I will draw from our experiences in Massachusetts, not to offer a model for replication, but to examine issues which I feel are critical if we are to comprehensively approach a service system design that is responsive to the unique needs of this population. Time does not permit a complete accounting of our efforts and this is available in other sources (Barrett, Carr, & Covert, 1987; Covert & Carr, 1988).

In 1984 a task force was commissioned within the state of Massachusetts to examine the service needs of individuals who are deaf-blind and how those needs were currently being met by state agencies. The task force consisted of consumers, parents, educators, and representatives from key state agencies. The impetus for this effort came from multiple sources: (a) anticipation of the transition from education to adult services of approximately 75 young adults who were deaf-blind during the years of 1987-90; (b) advocacy from consumers frustrated by case management systems that were inaccessible due to lack of expertise in communication and service needs; (c) parents who complained of being shuttled from agency to agency when seeking to identify adult service responsibility; and (d) a follow-up study of individuals who had previously transitioned from state and multi-state projects under Section 307.11 (formerly VI-C programs) which found that many of these individuals were confined to their homes without services and supports.

The task force examined more than a dozen services including residential, vocational, recreational, transportation, interpreter,

independent living, medical, social, and so on, requested by individuals who are deaf-blind and their families. Various aspects of these services could be accessed from at least nine different state agencies. As was expected, there existed huge gaps in the continuity of services needed by the range of persons who were deaf-blind.

A report issued by the task force identified service gaps in the aforementioned areas and developed numerous recommendations to address these gaps. Central to the outcome of the report was the realization of the need for change in the system of service delivery for individuals who are deaf-blind. I believe these recommendations are crucial in developing accessible systems of adult services. These include the following:

- The assignment of a lead agency, with responsibility as a point of entry into the adult service system, to coordinate all the resources of that system.
- A system of case management by personnel with background and expertise in assessment, communication, and development of comprehensive plans of service to meet the unique needs of individuals who are deaf-blind.
- Capacity to provide technical assistance and training to state and community agencies to promote accessibility for individuals who are deaf-blind.
- Coordination of program development to meet identified service gaps within the system.

Through coordinated advocacy and lobbying by parents, consumers, and professionals, the above recommendations were implemented by the state legislature through appropriation of funds. The State Commission for the Blind accepted responsibility as lead agency and utilized both new and prior funding sources to create a Program of Services for individuals who are deaf-blind. The program consisted of a director, supervisor, six case managers, and three persons with responsibility for program development, technical assistance, and training. The staff of this program functioned primarily as a team and consisted of persons with a broad spectrum of experiences in providing services to individuals who are deaf-blind and who are of differing ages and capacities.

The initial task of the program was to coordinate and develop a range of vocational and residential services for the population of individuals who are deaf-blind and transitioning from education to adult service programs. There were significant resources appropriated for this task and these services were developed for more than 75 people in a three-year period. Again, time and space do not permit me the opportunity to relate the full details of this accomplishment. I would like to highlight some key points:

- There is no one model of residential or vocational programs that we can prescribe for persons who are deaf-blind. A continuity of service options is needed that is responsive to and developed from individual needs, choices, and capacities.
- Communication and access to information from a variety of modes are essential for the achievement of quality of life goals in residential, vocational, and community domains and yet are often the most difficult to achieve.
- Resources for increased staff and availability for personal interaction need to be examined and included in program development. Along with the lack of funding, the lack of experienced persons and training options is the primary barrier to comprehensive program development.

I realize that the amount of resources available for the development of this program was unique. It is probably not realistic to expect a similar level of funds across all other state systems. Yet I believe there were also a number of benefits that centralization of case management within a lead agency had in improving accessibility of services for individuals who are deaf-blind. The majority of examples I will offer here were achieved without additional funding; instead they were achieved by examination of how existing resources could be coordinated and adapted for enhanced accessibility.

Centralized Information and Referral

The creation of this program provided consumers, families, and other agencies a single access point for information on resources available through state agencies for individuals who are deaf-blind. Given the communication needs of this population, I believe this is essential for system accessibility and individual empowerment through informed choices.

Coordinated Case Management

Case managers within the program had access to the social, vocational, and independent resources of the agency. This was crucial in the development of plans which supported the personal, living, and employment goals of individuals. Issues of communication, transportation, and acquisition of other supports were integrated across this planning and implementation.

Utilization of Specialty Support Services

Training and technical assistance were provided to other agency programs whose services were utilized by individuals who are deaf-blind. Examples include the integration of adaptive communication techniques within instruction in orientation and mobility, the inclusion of provision and training in use of hearing devices, and communication training within the agency program for individuals who are blind and over age 65.

Coordination of Inter-Agency Resources

During my time as director of this program, I cannot think of a single state agency's resources that were not utilized in some way in the development of a comprehensive service system. This ranged from minimal to major collaboration, but illustrates the continuum of services needed and the enormous task in providing accessibility for all individuals who are deaf-blind. Initially, we worked most closely with the Commission for the Deaf in enhancing the availability of interpreter resources and technology. We also assisted the Department of Elder Affairs in identifying and providing services to individuals with dual sensory impairment in nursing homes. We advocated within the Department of Mental Retardation for community placements for individuals who were deaf-blind and in state institutions. We collaborated with the Department of Mental Health to identify resources for out-patient and in-patient services.

Finally, do I believe we approached full accessibility and optimal individualization of services for all adults who are deaf? The answer is no. We struggled to obtain funds that would have replicated services such as those offered by the Deaf-Blind Service Center in Seattle, to be offered on a regional basis throughout the state. We were able to fund expansion of the programs of the Deaf-Blind Contact Center from Boston to include the central region of the state. We made inroads on accessing services through Independent Living Centers for the Deaf. We struggled with the state contracting system to provide flexibility to provide in-home residential supports. What I do believe was important is that we were working within a system to remove the barriers of that

system and gain improvements in service delivery.

I realize I have spent time illustrating state systems within a forum designed to examine federal systems and services. Yet I believe this was necessary to lay the groundwork for how Office of Special Education Rehabilitation Services (OSERS) directives can lead the way in initiating accessible systems of services for adults who are deaf-blind. It should be remembered that provision of adult services in state systems involves multiple agencies and community programs, of which rehabilitation is one aspect. I believe that leadership through the Rehabilitation Services Administration (RSA) could provide great benefit in the coordination of adult services for individuals who are deaf-blind.

I would like to return to some recommendations offered by Doug in his paper and then supplement with recently proposed recommendations by the National Coalition on Deaf-Blindness.

Recommendations

Personnel Training

Doug spoke to the integration of competencies in the pre-service and inservice curricula personnel preparation grants awarded by the Office of Special Education Programs (OSEP). I believe this recommendation should receive a strong endorsement and would like to add some additional details:

Targeted training programs. I believe this recommendation would be most beneficial if those programs are targeted that prepare professionals most likely to be involved in service provision to adults who are deaf-blind. Specifically these include preparation programs for rehabilitation counselors for individuals who are blind and individuals who are deaf, orientation and mobility specialists, and rehabilitation teachers.

Pre-service programs in education. In developing a system of community-based services for individuals who are deaf-blind in Massachusetts, our biggest obstacle, once funding was secured, was hiring staff with any expertise in working with individuals who are deaf-blind. Often contracts would go unbid or undeveloped. Our strategy was to fund at least one position in each program with a salary competitive with those offered in education programs and to recruit directly from those programs. The lack of funding of personnel preparation programs for education of individuals who are deaf-blind is compounded by the needs in adult services. With limited resources we must look to those programs to include competencies and expertise to cover both areas.

Agency staff development. In recent years RSA has cited deaf-blindness as a priority in agency staff development plans. It is imperative that this be supplemented by training materials and targeted competencies in service delivery. Too often, I fear this priority is translated into a sign language course rather than strategies for coordination of services. Also this development should be extended to community agencies receiving federal funds particularly in the areas of employment and independent living.

Choices and Control of Services

I would supplement Doug's discussion here by adding two points. First I think we need to speak to informed choices and choices of services that truly meet the needs of individuals who are deaf-blind. Services that are fractured and uncoordinated without planning or discussion of the unique needs of this diverse population do not present choices to consumers and families. They simply

offer frustration and struggle. We, as a collection of persons concerned about high quality services for individuals who are deaf-blind, have much work to do in examining options of services within adult services and translating those options into understandable choices for other consumers, families, and professionals. Creative plans developed through personal futures planning can identify individual capacities and needs for supports. Systems modification such as those offered through enhanced Individualized Written Rehabilitation Programs (IWRP) and model Medicaid Supported Living programs can offer those supports. Yet I believe there is an information and advocacy link that needs to be made if those services are to be accessible for adults who are deaf-blind. I will return to this point at the end of this paper.

Second, we must also remember that there are a large number of persons who are deaf-blind in state institutions and nursing homes. Without identification, advocacy, and assistance those persons are without choices, not just in service needs, but often in basic needs such as choices of food or clothing.

Inter-Agency Program Planning and Coordination

Doug has admirably articulated both a need and a vision for inter-agency coordination and service delivery for individuals who are deaf-blind. This is crucial if we are to approach true accessibility of services. I hope I have illustrated this need with some of our work and experiences in Massachusetts. I would reemphasize that, if our task is to advocate nationally and in individual states for a high quality life for all adults who are deaf-blind, and I would stress the word "all," then we must do the following:

1. Identify the diverse service needs of this population.

2. Identify the totality of services which rightly should be accessible.

3. Plan to offer those services in a coordinated delivery system addressing individual communication needs and supports.

I would further add that advocacy will only be successful if it is undertaken by a coalition of consumers, families, and professionals in education and rehabilitation. We cannot afford to be fractured or divisive if we are to undertake the task of improving adult service delivery for all individuals who are deaf-blind.

Recommendations of the National Coalition on Deaf-Blindness

Finally, I would note as important the position paper of the National Coalition on Deaf-Blindness on reauthorization of the Rehabilitation Act. This paper includes specific recommendations to RSA regarding improvement of rehabilitation services on a national level for individuals who are deaf-blind. Several recommendations have been stressed in my paper, specifically, vital needs in personnel preparation. Others include the following:

1. Monitor and mandate the inclusion in state plans of procedures for the delivery of rehabilitation services for individuals who are deaf-blind. Planning will include the following:

- assignment of lead agency
- prioritization in order of selection
- determination of appropriate evaluation and eligibility procedures
- casefinding, referral, and intake procedures

- coordination of support services for communication, vision, and hearing
- utilization of supported employment along with appropriate supports and observation of progress
- requirement that transitional planning begin at age 14
- specific development and coordination of independent living services

2. Issue a minimum of four 5-year grants targeting model service development and capacity building.

3. Adopt a uniform definition along with a specified coding and tracking system to provide data on the experiences of individuals who are deaf-blind who are receiving rehabilitation services.

4. Develop three multi-state demonstration projects in supported employment to examine a longitudinal data base of costs, benefits, supports, and sensory aids in accessing employment for individuals who are deaf-blind.

5. Target funding to advance research and training to further develop personnel training, program models and components, and use of technology.

6. Identify a minimum of one RSA staff specialist with people who are deaf-blind to monitor the development and content of individual state plans, provide technical assistance to state agencies, and provide oversight in target grant development.

I also urge RSA to work in collaboration with representatives of the National Coalition on Deaf-Blindness on the implementation of the above recommendations and to create dialogue on future initiatives.

The Missing Link

In closing, I wish to add that, over the last few years, a body of literature has been developed urging us to examine issues of quality of life for individuals with disabilities and to develop quality assurance planning in program development (Bradley & Bersani, 1990). In discussing this issue with Mary O'Donnell several weeks ago, I was reminded of something that happened when I was involved in the development of community residential programs.

At the time I was involved in a struggle with the administration of one program in trying to develop specific staff training and program components to address the communication needs of four persons who were deaf-blind. At the beginning of one of our meetings, when I was determined these issues would be resolved, the administrator handed me a copy of a quality assurance review of the program conducted by a newly commissioned family/citizen advisory board, which incidentally, did not include either family members or individuals who were deaf-blind. The report lauded the program as exemplary. It cited capacity measures of community participation, access to neighborhood resources, and variety in recreation activities. Indeed, these and other wonderful things were happening, but they were happening without any interaction with the individuals who were deaf-blind and living in the program. There were no modified calendars or systems to help people understand when activities would take place or to express opinions or choices about those activities. Several staff in the program were new, yet there had been no effort in training in the communication methods of the individuals. As a result, interactions around basic life needs were missed and ignored.

I believe this illustrates the link I referred to earlier in this paper. That is the link between what we know about "best practices" in

service delivery and "best practices" in providing services to individuals who are deaf-blind. We have a tremendous task ahead of us to forge that link, in order to translate "best practices" into daily practices, in promotion of a higher quality of life for all individuals who are deaf-blind.

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SELF-DETERMINATION: PRESENTATION

Janice Adams

Abstract: Barriers to development of self-determination include lack of opportunities to practice decision-making skills, negative attitudes of others including professionals and family members, poor independent living skills, lack of information about choices, and poor communication skills. To offset these barriers, the earliest possible intervention is recommended to provide options and allow practice in decision making. Teachers must be trained to hold positive expectations for these people and to allow them to participate in planning for their education. Education should provide access to interpreters, assistive devices, and training to improve communication skills. Children also need contact with positive role models and adult professionals who are deaf-blind. One way to achieve this is for those who are deaf-blind to attend the conventions of the American Association of the Deaf-Blind. Most of all we must work to provide emotional support to these people who may be fearful about making decisions that affect their future.

Self-determination. What automatically comes to mind? Courage? Overcoming obstacles? Willingness? Pushing oneself to do something? Exactly what is self-determination? Why is self-determination so important? What barriers to self-determination do people who are deaf-blind face? What is the relationship between independent living skills and self-determination? How do you boost self-determination? We will discuss each of these questions.

What is Self-Determination?

To clarify the meaning, we will refer to three dictionary definitions. Webster's Dictionary defines the word as "determination of one's acts by oneself without external compulsion." Random House Dictionary defines the word as "determination by oneself or itself, without outside influence; freedom to live as one chooses or to act or decide without another or others." The World Book Dictionary defines it as "direction from within, only without influence or force from without." These definitions of self-determination clarify our goal. Persons who are deaf-blind, family members, and service providers can work together as a team to reach that goal and improve the quality of life for people who are deaf-blind.

If self-determination involves the freedom to live as one chooses without external force, then obviously decision making is an important skill. The process of decision making is as follows: You first gather the needed information, make a list of choices, weigh the pros and cons of each choice, pick one of these choices, make a plan to accomplish your goal and execute the plan. So, many skills need to be learned by a person who is deaf-blind in order to have mastery over his or her own life. For a variety of reasons that will be discussed later, many persons who are deaf-blind miss out on the opportunity to develop those skills. Others often make the decisions for the person who is deaf-blind. The assumption may be that people who are deaf-blind cannot guide their own lives.

To keep things in perspective, it must be stated that none of us, regardless of our ability to hear or see, can be completely self-determined. We all have external forces which greatly affect the way we live. We

may make the decisions, but we cannot always guarantee the outcomes. Think about the times when you wanted to achieve something but you didn't. We have at one time or another felt discouraged or unmotivated to achieve a goal. And if we are honest enough with ourselves, we have even felt passive at times and did not pursue the goal of our choice. Furthermore, everyone has limitations to some degree. Some of these limitations are health, disability(ies), the environment in which we live, and our background (experiences, skills, education, etc.). Can you honestly say you can live just anywhere you choose to? Can you get just any job that seems desirable even if you have no qualifications for that particular job? In other words, you can be self-determined within your own realistic limitations. To illustrate, imagine yourself in a war-torn country. Because of the ongoing war, you are forced to live with some limitations. There may be food shortages. Schools, businesses, and agencies may be forced to close down. You may decide that you want to go to college in your own country but you also realize that all of the colleges are closed down for the time being. Your choices are limited. You may have to wait until the war is over or flee the country in order to go to college. When you are concerned about daily survival, the goal of attending college may be quite out of reach. The point is that you would need to be reasonable and know the limitations of your current situation. Only then can you make appropriate decisions within this sphere. When faced with limitations, we don't abdicate our self-determination. However, at the same time, we must be realistic. All humans must face this issue, not just persons who are deaf-blind. Everyone can strive to improve a level of self-determination, and even though all people have limitations of one degree or another, they can choose from among the options they have and learn to increase the number of options.

Why is Self-Determination so Important?

Some people may feel that the limitations for people who are deaf-blind are so great, why put forth the effort? To help stress the importance of self-determination, let us consider the example of two large companies. The first company does not allow its employees to have a say in its major (and minor) decision making. There is very little flow of information, not much creativity, low morale among the workers, low company productivity, and a high employee turnover rate. The other company considers workers' suggestions and ideas and allows them to influence its decision making. The second company seeks ways to empower the employees so that they can responsibly make decisions that affect their working conditions. Communication flows freely, creativity abounds, the workers enjoy their jobs, company productivity is high, and the employees tend to stay with the company. Many businesses have realized this principle that when employees feel a sense of involvement and control, they tend to be happier and more productive. They feel they are invested in the outcome and work harder to achieve the desired results. Self-determination for persons who are deaf-blind follows the same principle. If you exercise self-determination, you feel happy and productive, and you sense a greater likelihood of getting the results you want. A clear connection exists between self-determination and happiness, self-fulfillment, and self-esteem. Although it takes more effort initially, the final results make it all worthwhile. But it does take effort and there are barriers.

Barriers to Self-Determination

Barriers can be categorized into three basic types: attitudes, limited choices, and lack of experience.

Negative attitudes can stifle any one of us. Negative attitudes that stifle the development of self-determination can be found in family members, professionals, and even in persons who are deaf-blind.

Attitudes of family members play a major role in influencing the ability of children who are deaf-blind to develop self-determination. This influence can continue even when the person who is deaf-blind is an adult. Sometimes, parents do not allow their child who is deaf-blind to make choices or decisions. Along with this may come overprotection which prevents the child from going through different experiences that other children go through. Even choosing friends can become the sole responsibility of the parents. As a result, the child does not practice making decisions and realizing the outcomes of his or her own decisions. In adulthood, then, he or she is not prepared for self-determination.

Such negative attitudes may persist even when the person who is deaf-blind has many decision-making skills. I know one very capable woman in her 40s who is deaf-blind whose parents decided to put her in a nursing home. She refused to comply with the decision and stated she wanted to have her own apartment, take care of herself and live as independently as possible. Then the parents agreed but wanted to hire a live-in person to help her with daily chores. She again refused this arrangement. She was grateful that her family wanted to help, but as an adult, she naturally wanted to choose her own course in life, given her abilities and options. This woman exercised self-determination in this case and we must applaud her efforts to overcome intense family opposition.

Professionals who provide services to persons who are deaf-blind may carry negative attitudes. The low expectations for their clients who are deaf-blind may be due to a lack of experience and/or training. Until these two factors are recognized and addressed, decisions greatly affecting the lives of people who are deaf-blind will continue to be made without input from the client who is deaf-blind.

Schools are an ideal setting for teaching self-determination, but sometimes it is discouraged. Even young children can make decisions about what kind of toy to play with, but a teacher may present the child who is deaf-blind with one toy. It may take more time and effort to present the child with choices but it gives the child the beginning blocks with which to build self-determination. Even though a disabled child may be more limited than other students in some ways, teachers need to encourage decision making at every level. Another example of negative attitudes in the school system is found when it comes time for educational planning. A child who is deaf-blind, perhaps in his teens, may not be allowed to pick out classes and have a say in his IEP (Individualized Educational Plan). Most of us had the opportunity to choose courses which might affect our future. Adolescents who are deaf-blind need the same opportunity.

Negative attitudes about allowing persons who are deaf-blind to make their own decisions may be seen in the vocational rehabilitation system. It happens sometimes that a counselor will develop vocational goals for the client who is deaf-blind without much input from the client. Persons who are deaf-blind with employable skills have been denied any choice of training and employment and placed in sheltered workshops. In another case, the counselor may pick out vocational training for the client even though the client may have the ability and wish to go to college. Bypassing the wishes of persons who are deaf-blind

becomes an all-too-familiar experience which continues to inhibit self-determination.

When people express low expectations to children or adults who are deaf-blind, these persons who are deaf-blind develop negative attitudes about themselves. When a person gets a message repeatedly that says, "You can't do it," he or she will start to believe, "Oh, that's right, I can't do it because they said so." They may believe that it is better for others to make decisions for them. They have not been encouraged or given appropriate support in making decisions which affect their future. The low expectations become self-fulfilling prophecies.

Besides negative attitudes, we must consider personal limitations and limited resources. Personal limitations include the disabilities the person has. For example, those who have a severe or total visual loss will not be able to do activities that require vision, such as driving a car. Persons who are deaf-blind must be realistic about their physical limitations; however, they can still be self-determined within their limits. Some personal limitations result from lack of communication skills. If the person who is deaf-blind does not know how to communicate in the most effective way, his or her ability to make decisions is dramatically reduced. Communication skills are essential for using interpreters, having a sense of identity with other people who are deaf-blind, and communication with people in the community who have no experience with people who are deaf-blind. To limit communication training for a person who is deaf-blind is to limit his or her ability to be self-determined.

Another problem results from the limited availability of resources. People who are deaf-blind may have difficulty guiding their own lives because of lack of appropriate information to overcome obstacles, not knowing legal rights, lack of funding to purchase sorely needed equipment, and lack of contacts with appropriate agencies. Once the individual has accessibility, his choices can be much more expanded and self-determination is enhanced.

In addition to barriers caused by negative attitudes and limited choices, many persons who are deaf-blind encounter the barrier of lack of experience. He or she may have been overprotected by others or may have always had decisions made for him or her. When such a person does get the opportunity for self-determination, he or she is ill equipped. With little or no experience, the individual who is deaf-blind doesn't know how to make good choices.

The Relationship Between Independent Living Skills and Self-Determination

The more skills a child or person who is deaf-blind has, the more choices he or she has in life. Let us consider transportation, one of the independent living skills. If a person who is deaf-blind knows the different ways to travel and has experience riding buses, subways, train, taking cabs, sharing car pools, and walking, limitations are broken down. Other important skills include personal hygiene, money management, cleaning house, and laundering. The woman mentioned earlier whose parents had wanted to put her in a nursing home had to have these skills in order to get what she wanted. If a child who is deaf-blind is never taught to manage money early on, how can he or she decide to go into a store alone or even with someone else and pay for an item. So, gaining independent living skills is crucial for increasing self-determination for a person who is deaf-blind.

How to Increase Self-Determination

It can not be stressed enough that early intervention plays a key role in the development of self-determination in children who are deaf-blind as well as other children. Starting at the earliest age possible, we must give them options. Let them practice making decisions about which toys to play with, which activities to get involved in, which friends to have, which clothes to wear. It may take time for some children to understand that they do have choices. They may be unaccustomed to making decisions alone.

Education plays another key role in developing self-determination in children. First of all, proper placement is essential. Secondly, the teacher must hold positive expectations about the ability of children who are deaf-blind to learn to exercise self-determination. Numerous studies have proven that teacher expectations greatly influence their student's performance. Believe that children who are deaf-blind can make choices and they will. Allow children, if old enough, to be involved in the educational planning process. Give them access to appropriate classroom materials such as braille books, writing guides, equipment such as a Perkins brailler, and computers.

Communication skills can boost self-determination. With sign language, a person who is deaf-blind will have greater access to other persons who are deaf-blind and deaf. Interpreting services will allow for many more options. Besides sign language, other communication modes which are effective for communicating with nonsigners can increase self-determination. The more ways he or she can communicate, the more choices that person has. To illustrate, picture a man who is deaf-blind going into a store alone. Unless he has learned some alternative ways to communicate such as using print on palm, a raised alphabet card, or some other method, he might not be able to buy what he wants. But with these skills, a whole world of opportunity opens up for him.

Interpreters and support service providers play a role in boosting self-determination by bringing people who are deaf-blind into more contact with the outside world. This, in turn, allows more opportunities. Having assistance from interpreters and support service providers is not contradictory to exercising self-determination. The decisions are still made by the person who is deaf-blind without external force.

Another booster is family support. Families need to encourage their disabled child, but in order to do so, they may need to be taught how to do it. Participating in family support groups and/or organizations that focus primarily on parents with children who are deaf-blind can help parents encourage self-determination with their children.

Sensitive professionals can also provide a great boost. The professional can encourage the person who is deaf-blind to take appropriate risks and explore other options. Professionals who network with other professionals experienced in working with people who are deaf-blind will learn about additional options and opportunities to offer their clients.

Role modeling is highly effective and can take place on an individual basis, with groups, and with national organizations. For a person who is deaf-blind to meet another person who is deaf-blind who is in charge of his or her own life is a great inspiration and motivator. It helps to know they are not alone and they are not so "stuck" in their situation. Finding out how others handle situations helps the person who is deaf-blind to be more sure of what he or she can do.

Children who are deaf-blind can be inspired by contact with adult professionals who are deaf-blind. When schools and agencies that serve people who are deaf-blind hire adults who are deaf-blind in responsible positions, the children come to believe that they can likewise choose a career and have mastery over their own lives. Local social groups around the country where persons who are deaf-blind can get together also provide a ready source of role models. Support groups can be formed as well. Currently, Gallaudet University has two such groups—one for Gallaudet students and the other for members from the outside community. These two groups have proven worthwhile in encouraging persons who are deaf-blind to learn how to guide their own lives.

The American Association of the Deaf-Blind, a national organization specifically consisting of members who are deaf-blind, plays an important role by working for changes in legislature, advocating for legal rights, and providing an annual convention. These conventions offer excellent opportunities for persons who are deaf-blind to meet others and are especially helpful for those who are struggling with acceptance of their dual losses. After a week of activities with other persons who are deaf-blind, they usually feel encouraged and more confident that they can run their own lives.

The last but not least of self-determination boosters is emotional support. Because of the barriers mentioned before, persons who are deaf-blind may be fearful or reluctant about making decisions affecting their future. We must support them in their efforts. They will make mistakes, but we must let them learn from the mistakes. Instead of automatically telling them, "You can't do it," we must help them look for ways to make their plans succeed. Knowing that others are on his or her side, the person who is deaf-blind has a much greater chance of success.

Conclusion

We have discussed what self-determination is, why self-determination is so important, the barriers to self-determination, the relationship between independent living skills and self-determination, and how self-determination can be boosted. Some problems and solutions have been discussed in this paper as well. Although persons who are deaf-blind have more limitations than most other people, they can still make the decisions in their lives. They can still work to increase their options. It is obvious that self-determination is an important component of everyone's life—including the lives of those who are deaf and blind. What can we do now and what does the future hold for us? Let us put this information to good use. As we work toward increased self-determination for children, youths, and adults who are deaf-blind, we will see increased productivity, self-esteem, and happiness.

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SELF-DETERMINATION: REACTION

Barbara Ryan

Abstract: The components of a successful educational program include active involvement of the family from the beginning, extensive training for teachers in the area of dual sensory impairments, a language-based program with the use of individualized communication systems, a functional curriculum, and future-oriented objectives that reflect the goals of both the parents and the professionals. In addition, the medical profession needs more training and information in this field.

It is an honor to be presenting at the National Symposium on Children and Youth Who Are Deaf-Blind. With self-determination, I began my research for information on the topic, self-determination, at two universities. The results were discouraging. The ERIC and psychological searches under the topic of Self-Determination and Deaf-Blindness revealed a zero. Self-Determination and Disabilities revealed another zero. The ERIC journal articles for Deaf-Blind produced a dismal count of 48.

Janice Adams was kind enough to provide the foundation for my presentation. My focus is self-determination for persons who are deaf-blind with developmental disabilities. When referring to people who are deaf-blind with developmental disabilities I will use the term "deaf-blind."

Self-determination for the person who is deaf-blind begins with the family. Part H of the Individuals with Disabilities Education Act provides for early intervention services to children with developmental disabilities who are under three years of age. Early intervention services are required to be family centered, to provide service coordination, inter-agency coordination and development of a Individual Family Service Plan (IFSP) (Turnbull, Turbiville, Jones, & Lee, 1992). Early intervention services can empower families to assist their children in building self-determination. We can take this a step further for agencies providing services to families with children who are deaf-blind. The INSITE Model is a curriculum, with in-service training, that originated from the need to provide home-based programming for infants, toddlers, and preschool aged children who are multi-disabled sensory impaired. Incorporated into the INSITE Model are the P.L. 99-457 principles.

The family should apply knowledge gained from the IFSP during transition from early intervention to elementary education. If the transition is to have a favorable outcome, it is crucial that the family recognize the components of a successful educational program for children who are deaf-blind. One such component should involve a face-to-face parent interview before the Individualized Educational Plan (IEP) team meeting. The relaxed and less intimidating atmosphere of the family home allows the parents to freely express their needs, goals, and future expectations for their child. Also, when assessing educational programs, parents should seek those which employ teachers with a comprehensive pre-service or inservice education in the area of dual sensory impairments. A functional assessment should follow the formal assessment to assist the teacher with program planning. The parent should be a primary member of the functional assessment team. Parents should know that, without sufficient assistance in the classroom, the teacher will have difficulty executing the planned program. The parents

should also look for a language-based program with the use of individualized communication systems throughout the entire day. This is central to the child's development of self-determination. The child's inclusion within the general educational system can be another indicator of a beneficial program. A good educational program yields functional goals and future-oriented objectives constructed through collaboration between parents and professionals.

The medical profession has both helped and hindered the development of self-determination for people with developmental disabilities. As a parent and in my job as a Parent Specialist for California Deaf-Blind Services (one of the state and multi-state projects under Section 307.11), I have experienced each of these possibilities. Also, some families and teachers tell how the unenlightened, traditional prognosis given by some medical professionals can greatly reduce the quality of life for children and grossly undermine self-determination.

Recently, I visited a group home for three young men in their late teens who were deaf-blind from Congenital Rubella Syndrome. Their teacher was seeking help and requested the home visit. These young men's living quarters consisted of a converted garage with one tiny window which allowed only limited natural lighting. The rest of their world was just as dim; these young men had never been encouraged to develop self-determination. The oppressive, dismal conditions in which they survived were proof of this. My team member and I advised the foster parent about various ways she could assist the teacher and help these young men in learning new skills and enhancing their quality of life. Our suggestions were met with strong denials. She said none of the three had any ability to learn and, as evidence, produced a letter about one of the young men written by his family doctor. The letter, written about six months earlier, stated that, because of his disabilities, the patient was incapable of learning.

With the knowledge and information available today, there is no excuse for even one instance of this type of negligence. Apparently, medical professionals who are remiss in their treatment of persons with disabilities need training and education from informed medical and educational professionals and families.

Now, I will give an example of a family's experience with medical professionals that proved to be positive. Amy was born with CHARGE Association (CHARGE is an acronym that describes a cluster of abnormalities). After two years of life-saving intense medical intervention in the hospital, Amy was eventually able to live at home. As her medical condition stabilized, Amy's family turned to her doctors for a prognosis on Amy's cognitive abilities. The doctors' prognosis was to wait and see how she develops. That was just what the family needed to hear. The doors were left open for Amy's family and home teacher to create a dream about Amy's potential. Had the doctors' evaluation of Amy's cognitive abilities fostered low expectations, Amy's potential might have been suppressed.

Because of the rubella virus my daughter, Doria, is deaf-blind and is developmentally delayed. The challenge faced by Doria, her family, and the various professionals has been cultivation of Doria's ability to communicate.

Doria's desire to establish a viable communication system has been riddled with barriers. Soon after birth Doria became an outpatient at the University of California Los Angeles (UCLA) medical clinic. Doria was born with cataracts which were removed when she was 13 months old. She then

began to wear glasses. Even with correction by the glasses Doria was legally blind.

When she was five months old, I suspected she had a hearing loss. Doria's first attempts to communicate came in the form of manual signs. She wanted to wear her glasses and formed the sign for glasses in her effort to tell me this. Her attempt to communicate was ignored by the team of specialists at UCLA. They would only tell me to wait until my daughter was two years old and then she could be tested for a hearing loss. The audiogram identified a profound hearing loss. Doria began speech therapy. Doria's speech therapist did not encourage the use of sign language for fear that it would hinder her speech development. Even with the absence of sign language Doria did not develop speech.

Doria was four years old when the school adopted total communication as a language model. At that time total communication meant both sign language and speech were to be taught. This model seemed to be a good approach to me. However, this model had short-comings. Speech was a pull-out program taught in isolation in a nonfunctional context. Sign language was not taught within the confines of natural language development. Doria had to show competencies in the first four signs presented to her before new signs would be introduced. This model set low expectations of Doria's abilities.

During this time I took my first signing class. Signing to Doria at home did not produce outstanding results because we were a hearing family and not privy to the techniques used by parents who are deaf to teach their children natural sign language.

Doria's signing vocabulary grew as slowly as it was being taught to her. Doria's teachers, through the years, became frustrated with her slow progress with sign language. Just as with the sign language model, a nonfunctional teaching method was used with pictures and symbol systems. Community-based instruction and vocational training were functional activities that built Doria's skills, but the instruction for purposeful communication was missing. The cumulative effect of these problems took its toll on Doria, and she became very dependent upon prompts. Doria's initiative, pride, and self-determination were almost extinguished. At home, Doria became more difficult to live with.

After she graduated from school, her family began to work together to pull her out of this sad state. Objects paired with the sign, photographs, and partial participation were some of the strategies that were used by family members. Doria began to show progress. But the progress was slow because these strategies were not applied by competent care providers throughout her entire day. Doria's sister, Cynthia, felt she could help Doria develop at a faster pace. Cynthia became the paid daytime intervener.

"To act or decide without another or others" was one of the definitions for self-determination that Janice Adams cited in her presentation. That was our goal for Doria. Teaching choicemaking skills was crucial for fostering self-determination and individualized independence. One example of choicemaking was choosing what to eat from two or three food items. Doria was given every opportunity to make choices throughout the day. Quickly, the physical prompting was greatly reduced.

Enlarged photographs of family members and friends became an effective tool for expression and receptive communication. Her father's picture was handed to her when it was time to pack her bag for a weekend visit with him. Soon she was getting his picture from the shelf on Friday. That was

her way of asking if this was the weekend for a visit to her father's house. Photographs enabled Doria to know when and who was going to be visiting her or whom she was going to be visiting. A variety of paper bags with the imprint of the store logos were used to tell her where she would be shopping. She could also choose the restaurant of her choice by this method. The use of objects gave Doria concrete information. The tactile cues reinforce what she is unable to see from her vision loss and validate the signs that she can see when presented within her visual field. These strategies and more, paired with her sister's self-determination and love, could not fail. At the age of 27, Doria's knowledge, daily living skills, ability to communicate and sign language abilities continue to grow. Doria is now a beautiful woman with great self-determination.

Well, we have made the full circle from early intervention, population/demographics, family services, psychological/social, communication, personnel preparation, education, independent living, and adult services. I cannot summarize the outcomes needed for adult services for people who are deaf-blind as well as Doug Watson and Steve Perreault. It is our responsibility to blend our philosophies and build upon the knowledge expressed by all the presenters. The recommendations made at this symposium, if acted upon, give hope for the necessary improvement of the quality of life for the adults who are presently waiting for a chance to rebuild or enhance their self-determination. The children who are rapidly moving toward adulthood deserve to have an education that is responsive to their future. They deserve an education that supports and strengthens their self-determination.

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TECHNOLOGY

SOME CONSIDERATIONS FOR THE PRESENT AND FUTURE

David Goldstein

Abstract: The person who is deaf-blind can enjoy regular and rewarding contact with other people with the help of signaling systems, assistive listening devices, and computer-assisted communication aids. The presentation details these three areas of technology and presents a list of manufacturers, addresses, and phone numbers.

If we were to make a list of the disabilities for which modern technology can contribute most to an improved quality of life, deaf-blindness would be near the top. With the help of signaling systems, assistive listening devices, and computer-assisted communication aids, a person who is deaf-blind can leave behind some of the restrictions of one of the most isolating disabilities to enjoy regular and rewarding contact with the mainstream of humanity. From being restricted to communicating with people at arm's reach who must know a special communication method, this person can talk face-to-face or by phone with anyone who can type. Newspapers, and even television newscasts, are at his or her fingertips. No longer must he or she live in suspense wondering whether a friend will be unlocking the door to tell of his arrival. Instead, vibrations from a belt-worn signaler can alert the person who is deaf-blind to the doorbell, telephone, smoke alarm, and crying baby. The signals will provide essential information for living a secure and independent home life.

This is not to say that technology solves, or ever will solve, the problems of a dual disability. At best, it can mitigate them. However well it works, technology is generally costly, and therefore it is not available to everyone. Today's tools are often clumsy, complicated, or require extensive training. They may be designed poorly, with insufficient forethought, consumer input, or time for testing and redesign before they hit the market. Nevertheless, the difference technology can make, especially for children growing up with it, should not be ignored.

For most people, the idea of trying something new, of making a change, is fearful. This is natural and healthy, especially if it is associated with a bad experience. If you were one of the many people who are deaf who were forced to wear ill-fitting and painful hearing devices as a child, you will probably shy away from electronic gadgets that hearing people say will be helpful. You will be wary of the public's enthusiasm over cochlear implants, an enthusiasm which glosses over the operation and adjustment and the reality that they work as yet for only a very few. In fact, the idea of an artificial ear, or anything that changes the way we are used to perceiving the world, is scary.

The technology I will be talking about today is not like that. It is designed on the premise that deaf-blindness is a disability with certain characteristics. Instead of trying to eliminate the disability, it takes advantage of the remaining senses and helps us make the best use of them.

Available Technology

My talk will cover three areas of technology—signalers, assistive listening devices, and communication aids. I should tell you here that I am totally blind and have enough hearing to understand speech with hearing aids. My focus will therefore be on systems that vibrate, amplify, or give tactile output. For those with low vision, rest assured that for every braille letter or vibration, equivalents are available in the form of magnified print and strobe lights.

Signalers

Signalers can be sophisticated or simple. In fact, many people build their own. In my apartment I have two vibrators in my bed, one for the alarm clock, and one for the telephone. I connected the vibrator to the telephone with a relay device I picked up from Radio Shack. I can tell the difference between the clock and phone because the vibrator for the phone preserves the on-and-off pattern of a telephone ring. The system works fine—particularly when I forget to warn a guest to whom I have given the best bed in the house! For those who need to be alerted to more household noises, such as the smoke alarm or baby, and need to know about them from anywhere in the house, more sophisticated systems are required. Many people still use fans to stir up air currents. Now, there are systems which use radio signals. These consist of transmitters located at the source of the sound, which broadcast to a receiver worn at the user's wrist or belt. At least three companies make signalers that have been adapted to be used by people who are deaf-blind[1]. Signalers for the deaf usually employ lights, while adapted ones use vibrations.

The main challenge with such signalers is how to distinguish signals from different appliances--how not to answer the front door when the telephone is ringing. Usually, the way around this is to give each appliance a different pulsating pattern, such as one long and two short vibrations for the phone. Codes such as this are limited and, after four or five sources, they become indecipherable. Another approach is to use a single vibration for all. The user presses buttons on the receiver until he finds the one corresponding to the source of the signal. Systems often come with a "pager" that lets someone else in the house call the persons who is deaf-blind to come to a prearranged location for more communication.

Transmitters for the sound source vary from those wired directly, to portable ones that pick up the sound acoustically. While easier to install, acoustic systems may not always respond in critical situations. They also may not be able to discriminate between, let's say, the baby and a passing fire engine.

Because our present systems are often adaptations from devices on the general deafness market, companies often take the approach of making their already available systems accessible, rather than coming up with a perfect design for people who are deaf-blind. More willingness to spend time on thinking out new designs could lead to better systems.

While not exactly a signaling system, another simple device should be recognized here. This is the Tactile Speech Indicator, which conducts vibrations from the telephone to a disk on which the user places his hand. The user who is deaf-blind who can speak instructs the party he is calling to answer his direct questions by "no," "yes," and "please repeat," and counts the vibration of each syllable. This is a very portable device which can be used anywhere. The outgrowth of research, it is now distributed by Greg Verity of Port Washington, NY, who assembles it from a Radio Shack telephone amplifier[2].

Assistive Listening Systems

If someone has any degree of useful hearing, he will want to use it. I want to "hear" what you are saying. Hearing impairment, as with low vision, often requires more than a prescription of hearing aids to allow an individual to function comfortably in activities of daily life. Left to himself, the hard-of-hearing person learns to "make do." He may avoid difficult situations entirely or lip read, or find other strategies, many of which rely on visual cues. The blind person with a hearing loss has less to fall back on. Even if his hearing is relatively good, difficulty with localization, recognizing voices, disorientation, and inability to pick up essential information about people and the environment may make it difficult to cope.

There is actually a great deal of assistive technology available, although professional knowledge of it is not as widespread as it should be. The situation is improving. In a mood for making things accessible, and an effort to meet the needs of an increasing older population, many churches and theaters are adding listening systems. An advocacy group called Self-Help for the Hard of Hearing[3] is disseminating information about means to cope with hearing loss. Nevertheless, more work needs to be done to see that the needs of this disability group are understood and given proper attention in public places.

The temptation, when making a facility accessible to the hard of hearing, is to put in an amplifier and microphone and think that will take care of everything. It is not that simple.

The major characteristic of hearing impairment is that for each person it is different. Some people hear highs better than lows. Some can hear better through the bones around the ear than through the ear itself. Some can understand speech when it's made louder, while for others loudness may make it more garbled or cause pain. Others cannot tolerate sounds at certain frequencies. Some will have no trouble with amplified sound in an assembly room, while for others, the noise of other people milling about, or even the reverberation of the room itself, will be painful. Some hear better binaurally, while others need all sound from a central source. Some will benefit from hearing aids; others won't. One brand of aid will work better on a person than will another brand with the same specifications. Some will find headphones preferable, while others can use induction loops or silhouettes that fit behind the hearing aid and transmit the sound by induction. The list goes on. So when it comes to figuring out how to make the best situation for everyone, it is rare that one solution will fit all. Fortunately, assistive hearing devices, if installed the right way, can afford a good deal of flexibility.

Assistive listening devices usually, but not always, supplement a hearing aid, to help a person hear in a specific situation. A system that carries the sound of a television to earphones is one example of an assistive device. Of most concern here are those devices that carry the voice of a teacher or group of panelists to the hard-of-hearing person. Again, the device may be a simple commercial or home-made microphone and amplifier connected to the listener's headphones by wires, or a more complex system using radio or infrared signals to make a wireless connection.

The simple microphone on a wire may be placed at the center of a conference table, pointed at the person speaking or given to someone to speak directly into.

I often use a wireless auditory trainer. Mine is made by Phonic Ear, although there are several other companies that produce them[4]. By giving the lecturer the microphone which contains an FM transmitter, I can sit

anywhere in the room and hear what he or she is saying. (I can also hear that person as he or she leaves the room to make a phone call, or has a whispered conversation behind the scenes.) The best part about this device for me is that the closeness of the microphone to the lecturer eliminates most background noise. It is good for situations in which one person is talking. It does not work well for conference settings where interchange among several speakers is involved.

Infrared systems are normally used in public places where there may be several hard-of-hearing people in the audience. The signal is transmitted on a beam of invisible light to relatively inexpensive receivers that are usually available on loan from the box office.

Another approach often used is that of placing an induction loop around the periphery of the room. This only works for people who have a telephone switch position on their hearing aids. One of the problems with hearing aids today is lack of standardization about the power of their telephone coils. The loop may work for some people, but for others the hearing aids may not be powerful enough. Also, there are often spots in the room where reception may be poor. While portable induction systems may be adequate for small group meetings, I personally have not found the loop to be very reliable for permanent public access.

Whatever the transmission system used, the key is the placement of the microphone. It should be as close as possible to the person speaking to minimize background noise. I have been in too many theaters which have wonderful infrared systems, but which have the single microphone placed so far above the stage that it picks up as much ambient noise as a conventional hearing aid. A consideration for blind people is that if you have microphones hooked up to a monaural system, all ability to localize and hence know where the speaker is, will be lost. This may present problems in identifying who is speaking. However, setting up a stereo or binaural system may cause too much confusion or may prevent the most important sounds from going to the better ear. Obviously, you can't give a blind person a shotgun microphone to point to the person currently speaking in a room, since he won't know where that person is.

I wish I could give you suggestions for standards that could be set up for making every courtroom and public place accessible to the hard of hearing. Until systems improve, there seems to be no way to make an ideal setup short of giving everyone present his or her own microphone. I hope there can be more standardization among hearing aids, especially with regard to telephone coils, and that acoustics will be considered in the design of new buildings. All assistive devices should allow for connection of whatever transducer works best for a given individual. Also, public address systems—and all audio appliances, for that matter—should have readily accessible output connections to allow an individual to hook up his or her own hearing system.

In most cases, the hard-of-hearing person will be best equipped to say what works for her or him. In order to do this, however, this person must have a knowledge of, and opportunities to try out, as many options as possible. More demonstration centers for assistive hearing devices need to be established.

Computer-Assisted Communication Aids

In the late 1950s, the American Foundation for the Blind brought out its Tellatouch, a mechanical device that raises pins upward to form a single braille letter when someone types it on the keyboard[5]. In the late 1970s it became possible to produce electronic braille displays that could produce a line of

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braille at one time. Several systems use this technology to allow the user to read material one line at a time. When the first line has been read, the user pushes a key which advances him or her to the next line. Reading is done at the user's pace. These displays are used in stand-alone, all-purpose systems, such as the VersaBraille II from TeleSensory[6], Personal Touch from Blazie Engineering[7], and Alva Braille Carrier from HumanWare[8]; in computer access systems such as Navigator from TeleSensory[9], KeyBraille[10] and Alva Braille Terminal from HumanWare[11]; and in a dedicated device for the deaf-blind from TeleSensory called the TeleBraille[12].

TeleBraille II. Now in its second generation, the TeleBraille II combines a braille display and braille keyboard with an Ultratec telecommunications device for the deaf (TDD). The TDD has its own keyboard, visual display, and modem. Thus, the user can hold face-to-face conversations with someone typing on the TDD keyboard and read words on the braille display, and he or she can communicate over the phone with others who have TDDs through the TeleBraille's Baudot modem and, to a limited degree, can access computers also through its modem. The TeleBraille II can also be connected directly to an IBM PC. It costs about $5,500, but it is recognized as such an essential tool that many states and phone companies have programs to provide them to people who are deaf-blind[13]. It should be mentioned that Ultratec makes a large-print TDD for users with low vision[14].

The computer. Braille displays, costing anywhere from $3500 to $15,000, now give users who are deaf-blind access to computers. Probably the greatest benefit of the computer is that it can put disabled people on an equal footing with others. Just about anything that appears on a sighted person's screen, provided it is not graphic, can be rendered on a braille device. This has opened careers not only in the computer field, but in other areas for which the computer may be utilized, such as writing, editing, and record keeping.

The computer's flexibility can make it useful to people who are deaf-blind on all levels. In the classroom, it can provide touch windows and stimulation exercises that might motivate communication for low-functioning students with some vision. At home it can provide hours of recreation through games on any level. Right now, computerized preliteracy activities require some vision and are usually out of bounds to the totally blind person. Without meaningful tactile output, the only situation in which these programs might be partially accessible would be if the blind user has enough hearing to understand synthetic speech[15].

By connecting the computer to a modem, the user has access to databases such as CompuServe, where he can read newspapers, magazines and encyclopedias, make purchases through on-line stores with his credit card, or take part in live conferences with others using computers. I have had discussions on such systems with people who I had no idea were deaf-blind. One can connect a Baudot modem, such as the Krown SM85 Smart Modem[16], to a computer or stand-alone system, to turn it into a TDD. IBM has a system called the Phone Communicator[17], which lets the computer speak messages over the phone to a hearing person, and lets the hearing person spell out his replies using a regular Touch-Tone phone. This allows conversations with anyone, not just those who have TDDs.

Another device that should be mentioned here is the Braille Telecaption System from Dewtronics[18], which decodes television closed captioning for the deaf and transmits the written words to a computer for output to a TeleBraille or large print on the computer screen.

Stand-alone systems. These systems consist of braille displays, keyboards, and a simple computer in one unit. They may be used for writing, or be connected to modems, computers, and other communication devices. The most popular of these devices, the VersaBraille in its various forms, is no longer being manufactured. Others, such as the extremely portable Personal Touch, are not always easy to use. The Alva Braille Carrier features an Atari notebook computer that can be turned around to allow for face-to-face communication. The David, manufactured by Baum and costing $15,000[19], is a full 386 laptop computer with braille and speech, to which a variety of keyboards and modems may be connected. We need more simple stand-alone systems. If they are made small and designed properly, they could be a boon to those who do not have the need, capacity, or motivation to learn a computer and access system.

The Future

Everybody likes to talk about what the future holds. Many new ideas are currently being researched and some are in the first stage of testing. You will hear more about them when they are small enough to carry and more practical to use. These include voice recognition that could conceivably translate someone's speaking into large print or braille; a glove that can interpret a deaf person's fingerspelling, and someday sign language, into speech; and a mechanical hand that translates typed or computer input into fingerspelled letters.

What concerns me more than these future ideas is where we stand at the present. The tools we have out there now are by no means perfect. Unless we recognize the problems surrounding their development, distribution, and functioning, we will not be able to break out of trends that are already preventing technology from being as useful as it could be. I would like to leave you with 10 suggestions that I hope will be considered in discussions of standards and future development.

1. More flexibility. Many of the devices now on the market are designed under the assumption that everyone will use them the same way. As a result, they are not flexible enough to meet each person's needs. For example, the TeleBraille II, which many people who are deaf-blind find awkward to use, has no built-in provisions for connecting several TeleBrailles together for group conversations. A couple who is deaf-blind, who both have TeleBrailles, can talk to several members of their family at once over the phone--they use extension phones. But when the family comes to visit, conversation is restricted to one on one. What we need are more modular braille display devices that could be connected easily to keyboards, modems, computers, or to each other, so that systems could be customized to the requirements of each individual. Linking several displays together in a classroom or convention for deaf-blind could allow one interpreter to work with a group of people, just as sighted deaf people can take advantage of one interpreter. Such systems have been tried in Europe, but hardly any have been tried in this country.

2. Smaller and more rugged. It is well within the realm of today's engineering to make devices more compact and rugged than they are now. It is usually a problem with the display that causes a device to need repair. More systems would be in use if they broke less often and could be carried around more easily.

3. Ease of use. The devices now available are not as easy to use as they could be. One reason is that, as computers become more visually appealing for sighted people, the means by which we must access them

becomes more complicated. The problem of multiple windows and graphics can probably be surmounted, but the awkwardness of the solutions and amount of training necessary may leave many users who are deaf-blind behind. I believe manufacturers should spend more time designing devices especially for blind and deaf-blind users that would be easier to use and that would achieve the same end result as those used by sighted people. More work needs to be done, for instance, in making scanners for reading print easier to use by the average person who is deaf-blind.

4. More cues for people who are deaf-blind. Many devices for the blind do not give enough feedback for users who are deaf-blind. Prompts, capslock indicators, error messages, or new line indicators are given only through audible tones. Other methods should be explored, including vibrations and "tactiles," which raise pins over the place where a light would normally be.

5. More evaluation and testing before release. Historically, there has not been enough time allotted for pointing out problems in the design or malfunctions in a product before it is released. It is then too late to make the most ideal change in the design. Several recalls and upgrades are sometimes necessary to make corrections. Sending in a TeleBraille for repeated upgrades and repairs can be devastating to a person whose daily communication may be dependent on it.

6. Braille. Technology has not eliminated the need for braille. In fact, braille is the doorway to modern communication. Educators should teach braille to all people who are deaf-blind who can learn it.

7. Respect for low-tech. The luster of fancy push buttons should not let us forget that simple and noncomputerized devices remain as important as ever. Their use should be taught as part of our arsenal of tools.

8. Costs and technology legislation. Producers must be encouraged to make sure all means for lowering costs have been explored. Programs must be set up to ensure that each person is able to obtain the device he needs.

9. Opportunities to try things out. There need to be more ways for a person who is deaf-blind to try out a system before buying it. Even if one can get to a convention or demonstration center, the time one can spend with a device is too limited to be able to make any valid decision. Loan programs or visits from knowledgeable and unbiased specialists to the home or workplace should be explored.

10. More consumer input. People who are deaf-blind must have the opportunity to express their needs and participate in design and testing during the development of a device. It is true that we cannot always know what will be best for us--that is why people hire architects and decorators when planning a house. But unless the people for whom something is designed are involved in the process, the most beautiful and well-made appliance will have little practical use. In a situation where there is little to choose from, it is essential that manufacturers seek input from knowledgeable consumers and test their products in real-life situations. There is absolutely no point to technology unless it is the outgrowth of a sincere commitment to help people make the best of themselves and get the most out of life.

Resource List

1. At least three companies make signalers that have been adapted for people who are deaf-blind: Silent Call Corporation (produces Vibra-Call), P.O. Box 868, Clarkston, MI 48347, (313) 673-0221; Sonic Alert, Inc. (produces the Tactile Communicator), 209 Voorheis, Pontiac, MI 48053, (313) 858-8957; Quest Electronics, (produces Silent Page), 510 South Worthington, Oconomowoc, WI 53066, (414) 567-9157.

2. Tactile Speech Indicator: Greg Verity, 4 Levi Place, Port Washington, NY 11050, (516) 944-8356.

3. Self-help for the Hard of Hearing, 7800 Wisconsin Avenue, Bethesda, MD 20814, (301) 657-2248.

4. Some producers of wireless auditory trainers include Phonic Ear, Inc., 3880 Cypress Drive, Petaluma, CA 94954-7600, (800) 227-0735; Telex FM Systems, 9600 Aldrich Avenue, South Minneapolis, MN 55420, phone number not available.

5. Tellatouch: American Foundation for the Blind, 15 W. 16th Street, New York, NY 10011, (800) 232-5463.

6. VersaBraille II: TeleSensory Corporation, P. O. Box 7455, 455 North Bernardo Avenue, Mountain View, CA 94039-7455, (800) 227-8418.

7. Personal Touch: Blazie Engineering, 109 East Jarrettsville Road, Forest Hill, MD 21050, (410) 893-9333.

8. Alva Braille Carrier: HumanWare, 6245 King Road, Loomis, CA 95650, (800) 722-3393.

9. Navigator (see note 6).

10. KeyBraille (see note 8).

11. Alva Braille Terminal (see note 8).

12. TeleBraille (see note 6).

13. Many states and phone companies have programs for people who are deaf-blind. TeleSensory keeps a list of state services and phone companies that provide TeleBrailles. Contact Jane Mott-Smith at (800) 227-8418.

14. Large-print TDD: Ultratec, Inc., University Research Park, 450 Science Drive, Madison, WI 53711, (608) 238-5400.

15. For classroom and preliteracy activities for children, see "Our Kids Use Computers Too!" a workshop handout by Wendy L. Buckley, Perkins School for the Blind, 175 North Beacon Street, Watertown, MA 02172, (617) 924-3434.

16. SM85 Smart Modem: Krown Research, 129 Sheldin Street, El Segendo, CA 90245, (800) 833-4968. (This modem was recently discontinued due to lack of demand.)

17. Phone Communicator: IBM National Support Center for Persons with Disabilities, P.O. Box 1328, Building 5, Third Floor, Att. Paul Luther, Boca Raton, FL 33429, (800) 426-4832; for orders, (800) 426-3388.

18. Braille Closed Caption Computer System: Dewtronics, 987 Via Amorsa, Arnold, MD 21012, (410) 647-0769.

19. The David: Baum USA, AccessAbility Technologies, 17525 Ventura Blvd., Suite 303, Encino, CA 91316-3843, (800) 225-3150.

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